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The San Francisco AIDS Oral History Series

THE AIDS EPIDEMIC IN SAN FRANCISCO: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984

Volume I

Michael J. Helquist

JOURNALIST OF THE EARLY AIDS
EPIDEMIC IN SAN FRANCISCO

Jeannee Parker Martin, R.N., M.P.H.

THE AIDS HOME CARE PROGRAM OF
VISITING NURSES & HOSPICE OF
SAN FRANCISCO

Helen K. Schietinger, R.N., M.F.C.C.

NURSE COORDINATOR OF UCSF'S
FIRST AIDS CLINIC

With an Introduction by
Helen M. Miramontes, R.N., M.S., F.A.A.N.

Interviews Conducted by
Sally Smith Hughes, Ph.D.
in 1995 and 1996

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Introduction by Helen M. Miramontes, R.N., M.S., F.A.A.N., Associate Clinical Professor, Community Health Systems Department, School of Nursing, University of California, San Francisco.

Interviewed 1995-1996 by Sally Smith Hughes, Ph.D., for the San Francisco AIDS Oral History Series. Regional Oral History Office, The Bancroft Library, University of California, Berkeley.

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SERIES INTRODUCTION--Helen M. Miramontes, R.N., M.S., F.A.A.N.

Nursing and medicine were confronted with very similar challenges in 1981 when HIV infection surfaced as a new unidentified disease in the gay communities of San Francisco, Los Angeles, and New York City. At that time it was not known whether this new phenomenon, named Gay-Related Immune Deficiency (GRID), was infectious and contagious, and if so, how it was transmitted. Were nurses, like physicians, at risk for becoming infected if they provided care, and would their families also be at risk for contracting this disease? There was much speculation and controversy as to the potential etiology of the new disease. Some people including members of the impacted gay community, proposed that this new disease was the result of recreational drug use, such as "poppers" (nitrates) and indiscriminate anonymous sexual activity, as demonstrated by the popularity of bathhouses in the gay community, and not due to an infectious organism. A few very knowledgeable physicians/disease specialists, such as Don Francis, hypothesized that this new disease was caused by an infectious agent, probably a virus, and transmitted by means similar to hepatitis B. There was a lot of fear among health care providers about contagion, but there was also significant prejudice and discriminatory behavior because the new disease was identified in a population (gay/bisexual men) that was stigmatized by the larger society. Identification of the disease in people of color, especially African Americans and injection drug users, only exacerbated the biases, prejudices, and discriminatory behavior.

Many nurses demonstrated the same attitudes, beliefs, and behaviors seen in the larger society. I was a critical care nurse working in an intensive care unit (ICU) in a large teaching facility of a health maintenance organization in Santa Clara county. In the early years of the epidemic, it was not unusual to have two to three patients with *Pneumocystis carinii* pneumonia on ventilators in the ICU at any one time. Because some nurses avoided taking care of these patients, several of us volunteered to care for them on a regular basis. Inappropriate infection control techniques by health care providers, such as wearing gowns, masks and gloves for simple, nontransmissible activities, were the norm rather than the rarity. There were frequent breaches in confidentiality, not only among nurses but also among other health care workers. Similar situations occurred in San Francisco facilities as well.

Fortunately, some nurses rose above their fears and volunteered on a regular basis to provide the care and support required to meet the needs of these very ill and frequently terminal patients. Nurses also participated in community activities and organizations that were established to respond to this new disease. They creatively utilized the skills and expertise developed in caring for patients/clients in

traditional settings, such as hospitals, clinics, and homes, to establish programs in community-based organizations. I saw nurses training volunteers to provide practical and emotional support, educating their peers and the public about the disease, advocating for compassion and resources, working with families impacted by this disease, and participating in policy development and political action that was vital to enhancing community response to this growing epidemic. Some of these nurses were also members of the at-risk community; others had family or friends as members of the gay community, and others became involved as a response to the hysteria and fears within the health care environment. But all demonstrated core values of nursing compassion and care.

Individual nurses, such as Cliff Morrison, Helen Schietinger, Gary Carr, and others, did not hesitate to become proactive, not only in care, but also in advocacy. These nurses did not wait for the nursing organizations to initiate a response to the epidemic. In fact, it was individual nurses who pressured and guided the nursing associations to develop position statements, to provide testimony before legislative bodies, and to mount positive responses concerning the epidemic, educating nurses as well as the public. Traditional nursing organizations, like traditional medical organizations, were not only hesitant, but resistant to becoming aggressively involved in the epidemic. It was a few nurses within the California Nurses Association who provided much of the expertise in education and training that formed the foundation of a very successful statewide education and training program for providers funded by the state for ten years. And it was these nurses who also lobbied for funds and provided expert testimony on numerous pieces of state legislation. These California nurses also provided leadership at the national level with the American Nurses Association on federal legislation. Some of these nurses provided leadership in clinical settings as well.

It was Cliff Morrison, as a clinical nurse specialist at San Francisco General Hospital, who designed and implemented a special unit for people with AIDS (Pas). This special unit, with integrated treatment, care, and support services, became the "gold standard" for inpatient care and was duplicated across the country. Later Cliff became the deputy director of a large Johnson & Johnson Foundation grant that successfully implemented HIV/AIDS care systems, similar to the San Francisco model, in eleven cities across the country.

Nurses also implemented other services in San Francisco community-based organizations. One of the nurses, Helen Schietinger, established the housing program of the Shanti Project. These early models of nurses responded creatively and effectively to the needs of the statewide nurse case manager for home care developed in the mid-1980s by a nurse, Peggy Falkner, in the State Health Department Office of AIDS. The Ward 86, San Francisco General Hospital, Outpatient Clinic is world renowned for

the quality of care and the expertise of its staff, many of whom are nurse practitioners like Gary Carr. UCSF AIDS Clinic also has highly qualified nurse practitioners. Nurses were and are also significantly involved in AIDS Drugs Clinical Trials, including the San Francisco Community Consortium headed by Donald Abrams, M.D.

Nurses have always been involved with the poor and most vulnerable of a society's citizens. Each war, epidemic, and community disaster has had nurses in the middle of the crisis, providing a variety of services, care, and support. The AIDS epidemic is no different. In fact, in the early years before there was effective treatment, the caring of nurses was too often all that we could give. Often these nurses are not identified in the media or the history books; they are the "unsung heros." But it is often the nurse who sits with the patient and/or the family through the many critical episodes of AIDS; who counsels a person just receiving the positive results of an HIV test; who holds the hand of a dying person at night; who embraces a mother crying over the death of a son or daughter.

Some of us believe that everything in our professional lives, and sometimes our personal lives, has led us to this pandemic. The work has become a mission and we are committed to the long haul. Unfortunately, as of March, 1999, there appears to be no end in sight. The worldwide pandemic continues to rage out of control with 90 percent or more of new infections occurring in developing countries in Africa and Asia at the rate of 16,000 new infections per day. In some countries in the southern regions of Africa, 20 to 30 percent of the general populations are already infected. In this country, annual new infections have remained unchanged for several years and therapeutic drug treatments are not accessible to everyone who is infected. The need for nurses and nursing care continues to be vital and critical to our overall social response. Nurses will continue to participate and to use those nursing values and skills that best meet the need of people infected and affected by HIV/AIDS.

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March 1999
San Francisco, California

SERIES HISTORY--by Sally Smith Hughes

Project Origin

The idea for an oral history series on the medical impact of the San Francisco AIDS epidemic originated with Evelyne and David Lennette, virologists who have been following the history of the disease since its first recognition in 1981. In 1991, they began generously to provide support for interviews with physicians at the University of California, San Francisco [UCSF] and San Francisco General Hospital [SFGH] who were prominent in AIDS medicine in its earliest phase, 1981-1984. That series with twelve physicians, two dentists, and one epidemiologist--the AIDS physicians series--is now complete and available for research at the Bancroft and UCSF libraries.

The physicians' accounts made evident the critical role of nurses in AIDS history. It seemed imperative to capture their story. In 1994 we applied for and received a two-year award of \$60,000 from the University of California Universitywide AIDS Research Program to interview ten nurses active in AIDS nursing in San Francisco. We gratefully acknowledge UARP's support of phase 2--the AIDS nurses series--of the AIDS oral history project. Jointly sponsored by the Regional Oral History Office of the Bancroft Library, UCB, and the Division of the History of Health Sciences, UCSF, it significantly expands oral documentation of the AIDS epidemic. As in the earlier series, the focus is on the first three years of the epidemic when San Francisco led the way in many areas of AIDS nursing and medicine.

Primary and Secondary Sources

To prepare for the interviews, I used the documents and publications described in the "Series History" essay appearing with the AIDS physicians series oral histories. In addition, interviewees in the nurses series in several cases provided documents from their personal files which added immeasurably to the oral account. I wish particularly to thank Angie Lewis, Grace Lusby, Michael Helquist, and Helen Schietinger for the time they took to select, compile, and donate documents for the historical record. These documents will be deposited in the AIDS History Project Archives at UCSF Library.

The Oral History Process

The oral history methodology used in this project is that of the Regional Oral History Office, founded in 1954 and producer of over 1,400 archival oral histories. The method consists of background research in

primary and secondary sources; systematic recorded interviews; transcription, editing by the interviewer, and review and approval by the interviewee; deposition in manuscript libraries of bound volumes of transcripts with table of contents, introduction, interview history, and index; cataloging in national on-line library networks (MELVYL, RLIN, and OCLC); and publicity through ROHO news releases and announcements in scientific, medical, and historical journals and newsletters and via the UCSF Library web page (<http://www.library.ucsf.edu/>). The reader interested in the pros and cons of the oral history method is referred to the "Series History" in the AIDS physicians volumes.

Oral histories in the AIDS nurses series ranged in length from two to ten hours. Details of the interview process with specific individuals may be found in the interview history preceding each oral history transcript. The oral history volumes, tapes, and supporting documents will be available for research in the AIDS History Project Archives at UCSF Library.

Emerging Themes

ROHO's AIDS series consists to date of twenty-five oral histories on the medical and nursing response to the San Francisco AIDS epidemic in its first three years. There is a wealth of information on its medical, scientific, political, social, and personal aspects. Although it is impossible to do justice to this collection in a brief summary, the following comments suggest in broad outline the richness of the thematic material.

These oral histories with nurses continue the themes running through the physicians series--individual "preparedness" for the epidemic in both professional and personal senses; organizing medical, nursing, and social services in the face of a new and fatal disease; the epidemic's impact on the careers and emotional life of health care providers. Compared to the oral histories with physicians in phase 1, what is generally different about the oral histories with nurses is their portrayal of a day-to-day, hands-on, in-the-trenches engagement with the people most affected by the epidemic--the people with AIDS. Some of this distinction is due to the different requirements of the two professions. Put simplistically, physicians diagnose, treat, and prescribe for patients on an episodic basis. Their contact with patients, particularly in an incurable disease such as AIDS, may run for years, even decades, but is broken up into episodic bedside, clinic, or office visits.

Such is not the case with hospital nursing. As long as the patient is hospitalized, a nurse or nurses is caring for the patient in an immediate, personal, and ongoing fashion. The highs and lows of the nurse-patient relationship are difficult to escape, as these oral

histories indicate. Because nursing contact with patients tends to be more sustained and personal than is physicians', it is often more of a struggle to sustain a proper balance between personal involvement and professional detachment. Some of the nurses in these volumes speak of "burnout" as a consequence of over-commitment and of the measures they take to lessen or escape it.

The role of the gay community in AIDS activities is another persistent theme. The fact that six of the ten interviewees in this series are gay or lesbian is not incidental. In most cases, their sexual orientation was a basis for their original engagement in the epidemic, which to this day in San Francisco affects gay men in larger numbers than any other single demographic group. AIDS in the years covered by this project was widely perceived as a "gay" disease. The nurses in this series had the same perception and in many cases chose AIDS care as a way of assisting members of "the community", meaning the articulate and organized gay and lesbian community centered around, but not limited to, Castro Street in San Francisco. Thus it is inevitable, as these oral histories vividly demonstrate, that the history of AIDS in San Francisco, is inextricably intertwined with gay culture.

Yet another important theme is the impact of the epidemic on the stature of nursing. Although AIDS in San Francisco has always been a multidisciplinary activity, involving health care professionals, social and community workers, government agencies, etcetera, the interviews show nurses taking on more responsibilities, devising innovative services for holistic AIDS care, and assuming a stronger "voice" in the medical hierarchy. For example, it was nurses who organized and ran (of course with physician oversight), and continue currently to run the inpatient AIDS unit, Ward 5B (now 5A), at San Francisco General Hospital. Nurses also played a major role in structuring comprehensive patient management and community support systems which are a critical part of the multidisciplinary model of AIDS care for which San Francisco was known in the early epidemic. I hope the reader will be prompted to read on and to take from these oral histories much more than I have suggested here.

Locations of the Oral Histories

The oral history tapes and bound volumes are on deposit at UCSF Library's AIDS History Project Archives. The volumes are also available at the National Academy of Medicine, the Bancroft Library, UCLA, and other manuscript libraries.

Acknowledgement

We are grateful to Helen Miramontes, Associate Clinical Professor in the Community Health Systems Department at UCSF School of Nursing, for writing the introduction to the AIDS nurses oral history series. Ms. Miramontes has been involved with AIDS activities at the federal state, and local levels. At UCSF, she served as Deputy Director of the International Center for HIV/AIDS Research & Clinical Training in Nursing. In 1996, she was named to the Presidential Advisory Council on HIV/AIDS.

We gratefully acknowledge the support of University of California Universitywide AIDS Research Program, award # R94-SF-083.

Note Regarding Terminology

In this project, both interviewer and interviewee sometimes use the term "AIDS" to refer to the disease before it had been officially given this name in the summer of 1982. "AIDS" is also used to designate the disease which in recent years has come to be known in scientific and medical circles as "HIV disease". In these oral histories, the term "AIDS" has been retained, even when its use is not historically accurate or in tune with contemporary technical terminology.

Sally Smith Hughes, Ph.D.
Research Historian and Project Director

July 1998
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THE SAN FRANCISCO AIDS ORAL HISTORY SERIES

PHASE 1: THE MEDICAL RESPONSE, 1981-1984

VOLUME I

Selma K. Dritz, M.D., M.P.H., "Charting the Epidemiological Course of AIDS, 1981-1984"

Mervyn F. Silverman, M.D., M.P.H., "Public Health Director: The Bathhouse Crisis, 1983-1984"

VOLUME II

Donald I. Abrams, M.D., "The KS Clinic, Lymphadenopathy and AIDS-Related Complex, and the County Community Consortium"

Marcus A. Conant, M.D., "Founding the KS Clinic, and Continued AIDS Activism"

Andrew A. Moss, Ph.D., "AIDS Epidemiology: Investigating and Getting the Word Out"

VOLUME III

Arthur J. Ammann, M.D., "Pediatric AIDS Immunologist: Advocate for the Children"

Paul A. Volberding, M.D., "Oncologist and Developer of the AIDS Clinic, San Francisco General Hospital"

Constance B. Wofsy, M.D., "Infectious Disease Physician, AIDS Educator, and Women's AIDS Advocate"

VOLUME IV

Donald P. Francis, M.D., D.Sc., "Epidemiologist, Centers for Disease Control: Defining AIDS and Isolating the Human Immunodeficiency Virus (HIV)"

Merle A. Sande, M.D., "Infectious Disease Specialist: AIDS Treatment and Infection Control at San Francisco General Hospital"

John L. Ziegler, M.D., Ph.D., "Oncologist: Kaposi's Sarcoma and AIDS Research in San Francisco and Globally"

VOLUME V

Herbert C. Perkins, M.D., "Director, Irwin Memorial Blood Bank: Transfusion AIDS and the Safety of the Nation's Blood Supply"

VOLUME VI

Deborah Greenspan, D.D.S., D.Sc., "Oral Manifestations of AIDS"

John S. Greenspan, D.D.S., Ph.D., "AIDS Specimen Bank, UCSF"

IN PROCESS

Jay A. Levy, M.D., Virologist, UCSF: Isolation of the AIDS Virus

Warren Winkelstein, Jr., M.D., M.P.H., The San Francisco Men's Health Study, UC Berkeley

PHASE 2: THE RESPONSE OF THE NURSING PROFESSION, 1981-1984

VOLUME I

Michael J. Helquist, "Journalist of the Early AIDS Epidemic in San Francisco"

Jeannee Parker Martin, R.N., M.P.H., "The AIDS Home Care Program of Visiting Nurses & Hospice of San Francisco"

Helen K. Schietinger, R.N., M.F.C.C., "Nurse Coordinator of UCSF's First AIDS Clinic"

VOLUME II

Gary Stephen Carr, R.N., Ph.D., F.N.P.-C., "Nurse Practitioner at the AIDS Clinic, San Francisco General Hospital"

Angie Lewis, R.N., M.S., "Nurse Educator in the San Francisco AIDS Epidemic"

IN PROCESS

Gayling Gee, R.N., M.S., Clinical Nurse at the AIDS Clinic, San Francisco General Hospital

Diane Jones, R.N., Staff Nurse at the AIDS Clinic, San Francisco General Hospital

Grace Lusby, R.N., Infection Control Nurse, San Francisco General Hospital

Diane Miller, Director of Hospital Planning, San Francisco General Hospital

Clifford Morrison, M.S., M.N., R.N., F.A.A.N., AIDS Clinical Coordinator, San Francisco General Hospital

PHASE 3: THE RESPONSE OF COMMUNITY PHYSICIANS, 1981-1984 (ALL IN PROCESS)

Ric Andrews, M.D., Psychiatrist

Robert Bolan, Jr., M.D., General Practitioner

James Campbell, M.D., Internal Medicine

Stephen Follansbee, M.D., Infectious Disease Specialist

James Groundwater, M.D., Dermatologist

Paul O'Malley, M.D., Communicable Diseases

William Owen, Jr., M.D., Primary Care

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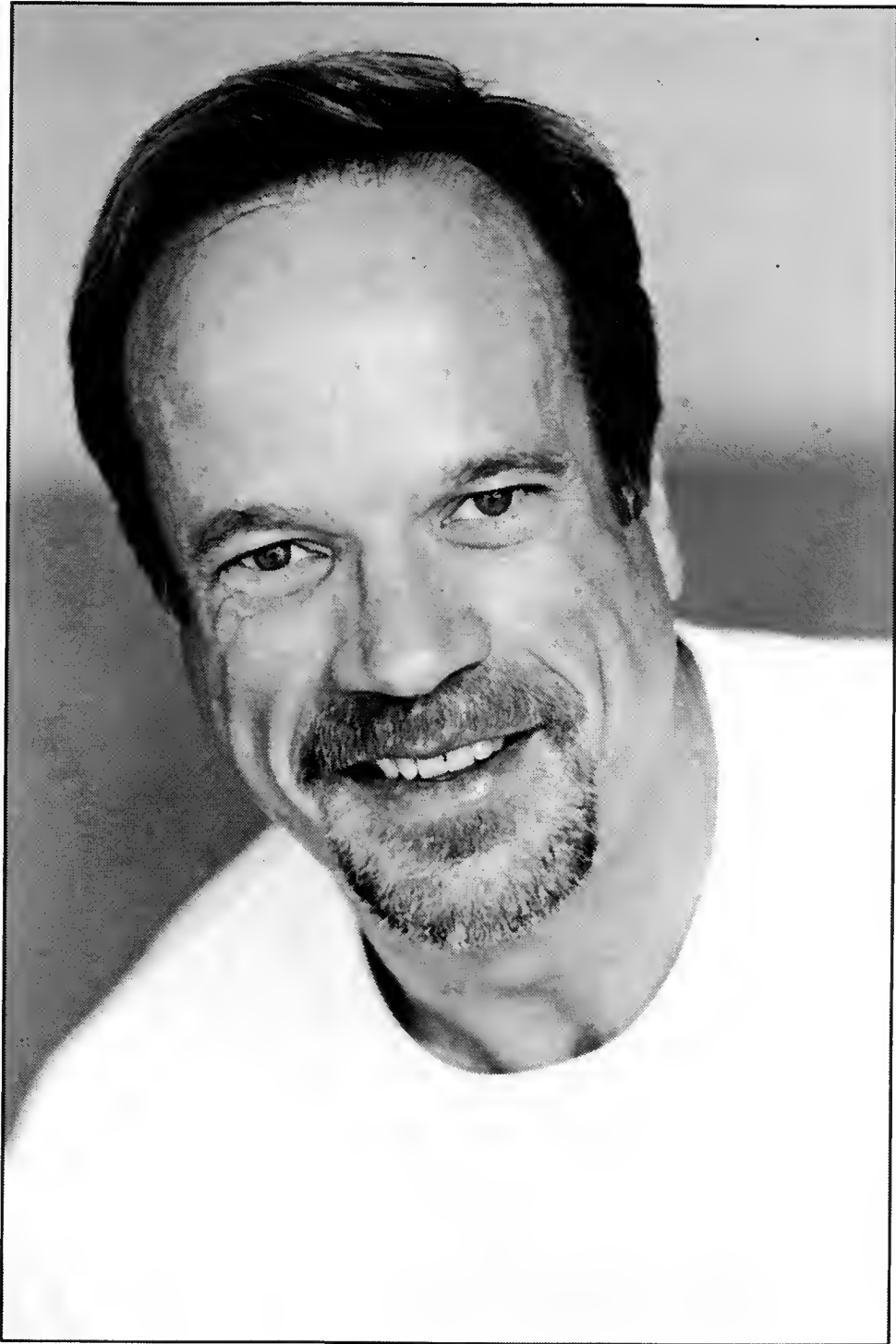
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THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984
VOLUME I

Michael J. Helquist

JOURNALIST OF THE EARLY AIDS EPIDEMIC IN SAN FRANCISCO

An Interview Conducted by
Sally Smith Hughes, Ph.D
in 1995 and 1996



Michael Helquist, 1998.

INTERVIEW WITH MICHAEL J. HELQUIST

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INTERVIEW HISTORY--by Sally Smith Hughes

Michael Helquist is a journalist who was interviewed for the oral history series at the suggestion of Helen Schietinger because of his critical role as a link between the world of medical science and the gay community. His oral history provides an overview of community reaction to the early epidemic and also brings it down to the personal by describing its effect on his own life when his partner succumbed to AIDS. Helquist's articles in the gay and straight press and his regular column "The Helquist Report" in The Advocate provided the gay community, which the epidemic in San Francisco hit first and hardest, with practical information about AIDS. Baffled and afraid of a disease which the biomedical profession could not adequately explain--the causal virus was not definitively identified until 1984--those touched by the epidemic sought information in language that they could understand and which respected community mores. Helquist's journalism filled the bill on both counts.

In the interviews, Helquist tells of his friendship and later partnership with Mike Feldman, one of the most visible of the first one hundred or so individuals diagnosed with AIDS in San Francisco.¹ Helquist's memory of his lover, who eventually died of AIDS, is a feature of the interview. He tells of accompanying Feldman to the Kaposi's Sarcoma Clinic at UCSF where a patient faced a battery of specialists and laboratory tests at a time when little was known about disease progression or the causal agent. Helquist rekindled his memory of this trying time by referring repeatedly during the interview to Feldman's diary which contains a day-by-day account of his experience of AIDS.

Hinting at his longstanding rivalry with Randy Shilts, the San Francisco Chronicle reporter on AIDS and author of And The Band Played On,² Helquist contested Shilts' reputation as the journalist of the epidemic. Although Helquist acknowledges Shilts' contributions to AIDS journalism, he points out that his own articles and those of other journalists played a substantial and sustained role in reporting the San Francisco epidemic.

Helquist also made a point of acknowledging the prominence of women in early AIDS activities. They not only contributed to all aspects of health care but their presence provided gay men with a model

¹ For more on Feldman, see the appendix.

² Randy Shilts. And The Band Played On: Politics, People, and the AIDS Epidemic. New York: Penguin Books, 1988.

of compassion and emotional support which in his opinion helped to form a more inclusive gay and lesbian community.

The Oral History Process

Helquist's pleasant home in San Francisco's Noe Valley was the location of a single interview session on March 25, 1995. Prior to the meeting, he had sent his curriculum vitae and, most helpfully, a letter enumerating the topics he wished to cover in the discussion, which indeed we did. Helquist spoke feelingly of his experiences of the epidemic in several capacities: as a freelance reporter, as a partner of a person with AIDS, and finally as one who at the time of the interview had experienced a bout of *Pneumocystis carinii* pneumonia, a marker of AIDS.

The edited transcripts were sent to Helquist who returned them lightly edited. He also supplied a carefully organized portfolio of his papers, a few of which have been placed in the appendix. The remainder have been deposited in the AIDS History Project Archives at UCSF Library.

This oral history provides an insight into the gay community's early response to the AIDS epidemic, by a reporter who, although not formally trained in biomedicine, took on the responsibility of helping to interpret for his community a new and devastating disease.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

Sally Smith Hughes, Ph.D.
Research Historian and Principal Editor

July 1998

Regional Oral History Office
Room 486 The Bancroft Library

University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name MICHAEL J. HELQUIST
Date of birth 04-04-49 Birthplace PORTLAND, OR.
Father's full name LESTER J. HELQUIST
Occupation Retired, ^{Hardware Store} Mgr. Birthplace Minneapolis, MN.
Mother's full name EVA B. GATES
Occupation Retired Birthplace BOONE, IOWA
Your spouse DAVID ZUCKER
Occupation SR. VICE-PRESIDENT
PORTER NOVELLI Birthplace _____
Your children N/A

Where did you grow up? PORTLAND, OR.
Present community SAN FRANCISCO, CA
Education — see attached resume —

Occupation(s) _____

Areas of expertise _____

Other interests or activities _____

Organizations in which you are active _____

MICHAEL J. HELQUIST
 2115 S Street, N.W., #2B
 Washington, D.C. 20008
 Res: (202) 234-3943
 Bus: (202) 862-3861

OBJECTIVE: HEALTH COMMUNICATION ANALYSIS AND PROJECT MANAGEMENT

SUMMARY: Experienced project manager, published editor and journalist with 15 years U.S. and international experience. Particular expertise in:

- Management of \$24 million U.S. government project for public health communication in 40 developing countries.
- Development of 25 community-based education and communication programs in 10 countries.
- Publication of more than 500 articles and three books on health promotion and policy analysis.

PROFESSIONAL EXPERIENCE: ACADEMY FOR EDUCATIONAL DEVELOPMENT,
 Washington, D.C.

1973
 1987-~~Present~~

1993
 Project Director (1991-~~Present~~)

Director of programs and activities worldwide for the AIDS Public Health Communication project (AIDSCOM). Provide guidance and monitor implementation and evaluation of AIDSCOM programs in Africa, Latin America and the Caribbean, and Asia. Supervise staff of 25 in the U.S. and in seven emphasis country sites.

Selected Accomplishments:

- Coordinate management of a \$24 million budget.
- Coordinate research and intervention studies with cross-regional applications.
- Coordinate diffusion and dissemination of research data and lessons learned from project studies.
- Represent AIDSCOM at major national and international AIDS and health conferences.

Regional Coordinator, AIDSCOM (1987-1991)

Regional coordinator for programs in 11 countries in Latin America and the Caribbean. Supervised nine technical staff in the U.S. and in four AIDSCOM emphasis country sites. Manage a regional budget exceeding \$2.5 million.

Selected Accomplishments:

- Coordinate research and intervention studies with inter-regional applications, develop intervention activities among individuals with high-risk behaviors.
- Design AIDS communication campaigns that integrate mass media and face-to-face interactions.

MICHAEL J. HELQUIST

Page Two

INDEPENDENT CONSULTANT, San Francisco, CA1984-1987**International Health Consultant, Freelance Journalist**

Provided technical assistance to local, national, and foreign governments and community organizations for policy development, program planning, implementation, and evaluation. Editor, writer, and columnist for national publications and writer of health promotion materials.

Selected Accomplishments:

- Editor and co-editor of three published books on public health issues.
- Founding editor of international monthly newsletter on mental health issues (1986-present).
- Columnist for national publication on health policy issues.
- Assisted with development of international seminar for World Health Organization.
- Interviewed by TIME, Newsweek, ABC, NBC, CNN, Australian Broadcasting Corporation, Radio Netherlands.

**PRIOR
EXPERIENCE:**UNIVERSITY OF CALIFORNIA, San Francisco, CA1980-1984**Editorial Assistant**

Helped edit and produce scientific journal papers. Conducted literature reviews of numerous publications.

CITY OF EUGENE, OREGON, Eugene, OR1975-1980**Coordinator of Social Services**

Directed outreach program for elderly population. Recruited and supervised three staff and 65 volunteers.

EDUCATION:

B.A. (History, Literature), State University of New York at Albany, Albany, NY

**AFFILIA-
TIONS/MEM-
BERSHIP:**

- American Public Health Association
- International AIDS Society

INTERVIEW WITH MICHAEL HELQUIST

I AUTOBIOGRAPHY

[Date of Interview: March 24, 1995] ##¹

Arrival in San Francisco, 1980, and First Jobs

Hughes: Michael, start, please, with a thumbnail sketch of yourself.

Helquist: I guess the relevant sketch would begin probably early in 1980, when I moved to San Francisco from Oregon, where I was born and raised. Initially, I came here because I just wanted to live in the city. It wasn't just because this was a gay mecca of the time; it was also a big city for me, and I wanted to be part of the excitement.

My first job in the city was at UCSF in the personnel department. I was there for a couple of years [1980-1982]. Then I moved to another department, Extended Programs in Medical Education [EPME], as editorial assistant, 1982-1984. I was fortunate to have someone in the department, Dr. Barbara Gerbert,² who is still at UCSF, who really wanted to be very supportive of my writing, which was at a stage of my just talking about wanting to write and not sure what I meant.

And jumping ahead a little bit, I was fortunate that she chose to be a sponsor for me. After I stopped working at the university, Barbara paid me a stipend for about six months to support my writing so I could get started on it, which was a major boost.

Hughes: What kind of writing?

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

² Dr. Gerbert was assistant professor in the UCSF School of Medicine.

Helquist: We were thinking initially that I would write a book, and we thought that it might be with an AIDS theme, because my involvement with AIDS had begun in the fall of 1982. I continued working at UCSF until the summer of 1983, and then she provided funds to support me. I did not complete a book at that time; I became a free lance reporter and journalist, and published articles. In the years following, I edited several books and other publications.

Hughes: Mainly on the epidemic?

Helquist: Yes. I really was at the right time at the right place. I had been working a little bit, writing for one of the gay newspapers, Coming Up!,¹ here on various subjects, and initially, I wanted to do a history of Valencia Street, including an oral history for whatever remained of Valencia Street as it was developing. At that time, Valencia Street seemed like it was going to be the next area to "happen" in the city, which didn't quite pan out.

¹ Now the San Francisco Bay Times.

II THE AIDS EPIDEMIC

Writing about and Working in AIDS

Helquist: Part of the reason why Valencia Street was important to me was that while working on the history I made my first contact that got me into AIDS writing. I happened to be one day walking by New College, which is located on Valencia, and happened to just start talking to someone on the street who worked there, and this person was Mark Feldman. Mark was probably one of the first hundred in the city to be diagnosed with AIDS.

When I met Mark, he hadn't been diagnosed, but we struck up an intermittent friendship that became quite a bit more developed, especially when he was diagnosed at the end of November in 1982. It was really my association with Mark that also gave me a boost in writing, because he was one of those early people who wanted to be public about having AIDS. So I ended up interviewing him and publishing the interview,¹ interviewing his parents,² and others who were in his new life that revolved around AIDS.

So it really gave me a push and a start for writing, which I continued with until 1987. My writing on AIDS was for a number of papers, both gay community publications nationwide and publications like the American Medical News, Ms Magazine and the San Francisco Bay Guardian.³ So I was very much involved in

¹ "Mark Feldman: A Personal Look at AIDS" by Mark Feldman as told to Michael Helquist. Coming Up!, January 1983. [Many of the footnote references throughout this oral history were supplied by Helquist.]

² M. Helquist, "Parents and Lovers Confront AIDS," Coming Up! January 1983.

³ Also including New York Native, the Los Angeles Advocate, and the Washington, D.C. Gay Blade.

AIDS writing and for San Francisco, I wrote some of the very earliest articles about issues like the HIV connection with substance abuse,¹ which wasn't very prominent in people's minds, and some about the involvement in AIDS of women in the helping professions.²

There was this initial phase of doing a lot of writing and getting very focused on it, which also led me to do consultant work for the CDC [Centers for Disease Control] and for the World Health Organization [1987-1988] just when WHO [World Health Organization] was beginning their AIDS program [Global Programme on AIDS]. My involvement kept increasing each year: participating and presenting at the International Conferences on AIDS and writing for international publications.

My consultant work with WHO, CDC, and several AIDS organizations led to a job in Washington D.C. The federal government, through the state department, funded a five-year, \$15 million AIDS project designed to assist developing countries to develop effective HIV prevention programs. This program, begun in 1987, was called AIDSCOM for AIDS communication, since we focused on using communication channels: TV, radio, print, person-to-person, to support AIDS prevention. I worked for a non-profit contractor; my position was initially as program officer and editor, and I primarily focused on the English-speaking countries of the Caribbean.

I continued working in D.C. until November of 1992, and then I was able to bring my part of the job to San Francisco and work here for the final year of the project. In the spring of 1993, I was diagnosed with AIDS due to low T-cell counts. In October of the same year, I had my first opportunistic infection, *Pneumocystis pneumonia*. Soon after I retired due to AIDS-related disabilities. And that pretty much brings us up to date.

¹ M. Helquist, "The Neglected Risk Group: IV-Drug Users," Coming Up!, San Francisco, January 1985.

² M. Helquist, "Women Respond to AIDS," Our Paper, San Jose, September 1983; Also: M. Helquist, "Coping with the Tragedy of AIDS," Ms Magazine, New York, February 1984.

First Encounter with the AIDS Epidemic

Hughes: Do you remember how you first learned of the epidemic?

Helquist: It was either reading one or two of the early articles that had been written--

Hughes: Here?

Helquist: Here, in the gay papers. The person who had started writing the first personal experience AIDS column in the San Francisco Sentinel, Bobbi Campbell, was a nurse at UCSF. It was both that column and, in the very early days, what most people heard about or saw were these posters that were posted in the window of the drugstore at 18th and Castro Streets--which today is Walgreen's and used to be Star Pharmacy. Those were photos of KS [Kaposi's sarcoma] lesions, with advice to "check yourself daily for lesions."

Hughes: Bobbi Campbell's foot, right?

Helquist: Oh, yes, it probably was.

Hughes: Was there more than one?

Helquist: More than one poster?

Hughes: I mean, of different types.

Helquist: I think probably there was one with the photo, and then an accompanying one with more information, written information. But even then, it was still so early in the epidemic that you were kind of aware of it, but it wasn't top of mind. It quickly got there, but for a while, it was just this weird sort of thing going on, which of course initially was called the gay cancer. It took awhile for people to absorb this new information and to realize how it affected their lives.

We know AIDS became more real and personal for the "general population" once Rock Hudson's diagnosis and death were revealed. For the gay population, we began to have similar experiences, but much earlier. For example, when Patrick Cowley, the San Francisco musician and producer, died of AIDS in

November 1982, the community was shocked and saddened. AIDS was becoming more real and more of a threat.¹

Defining the Disease

Hughes: How did people feel, you included, of course, in having the disease labeled "gay cancer" and defined as a disease of homosexuals?

Helquist: I think initially, we accepted it as, This seems to be something that's only hitting gay men; there is a cancer involved; shorthand, it comes out gay cancer. There were others who were certainly quicker than I was to say, Wait a minute, we're looking at trouble here. It was very clear to them that power rested, as it always does, with people who name an event or a disease.

At that time [1982-1983], there were no national mainstream meetings about AIDS. This was certainly long before any of the AIDS conferences, the international ones.² But there were gay-lesbian health associations, and there was definitely a time when that group, which included influential people in the medical field, made a very definite effort to say, "We have to change this name."

Then it became clearer what the issues were. But also during the early days, we didn't think of it as much more than cancer. I mean, KS is what was on everyone's mind. You would get into a routine of every morning while, say, taking a shower, where you would be looking for spots, and being sure to look on the soles of your feet, not just wherever else.

¹ Patrick Cowley wrote, arranged and recorded several albums in the late 1970s and early 1980s in San Francisco. He had six records on national pop, soul and disco charts. Cowley died on November 12, 1982. He was 32 years old. (See "Producer's Quest for Death with Dignity," Datebook Cover Story, San Francisco Chronicle, 5 December 1982). [MH's note]

² The First International Conference on AIDS occurred in June 1985 in Atlanta. [MH's note]

Hughes: So the other infections that are now recognized to go along with AIDS were not very prominent in people's thinking? PCP [*Pneumocystis carinii* pneumonia] was the first condition reported in the medical press.

Helquist: Right.

Hughes: And yet, PCP doesn't seem to be the thing that caught people's attention. Why was that?

Helquist: Maybe because the gay cancer, the lesions, were so dramatic and visible, and had all the stigma, whereas the pneumonia, at least, sounded like something a little bit more familiar. Gay men thought, "Okay, it's a different kind of pneumonia, whatever that means. I can't say the word [*Pneumocystis*] anyhow." If you're sick with pneumonia, you're sick in bed or in the hospital or whatever. With KS, you could walk around and people could see you, and it was much scarier for that reason. But there were definitely people who were dying with KS and *Pneumocystis* even in those early days.

Mark Feldman

Treatment at UCSF

Helquist: I am trying to find a reference here [leafs through journal] in this diary of Mark Feldman's. He gives the date in here of when Pat Crowley, who used to be a roommate, died. I think he said that Pat died of KS and *Pneumocystis*. [tape interruption]

This journal of 1982-83 of Mark Feldman's provides a picture of when someone would go for medical care, or at least when he did. And looking back on it now, he probably could have been diagnosed maybe a full year before he was--knowing what we do today. There were enough weird symptoms coming on that were unusual, but he didn't actually seek specific medical advice until right before Thanksgiving in 1983.

The first mention that he makes is seeing Don Abrams¹ at UCSF. At that time, Dr. Abrams noticed the candidiasis in his mouth, and he directed Mark, "Go look in the mirror and see what I'm talking about." That scared Mark, and he looked in the mirror, and he said, "Oh, you want me to look at these two purple splotches in my mouth?" And Don said, "Well, no. Let me see." So it was Mark who actually saw the KS lesions first.

Then he writes in his journal about the really awful days that he went through, not just hearing the news, but on that very first day, he was up at UC Med Center from ten a.m. to four p.m., and he went from Abrams' office to Dr. [Francine] Lozada, who is dermatology--

Hughes: No, dentistry, oral lesions.²

Helquist: Right. She took one look in his mouth and said, "KS." And then she biopsied it. He was having all these tests done, and he was walking back to Dr. Abrams' office, and his mouth filled up with blood, so he had to go back to Lozada and eventually get it cauterized to stop the bleeding. Some of the difficulty Mark had was with managing his own health care, from offices to clinics. Kind of being on his own--someone wasn't walking him through the system and that was very hard. It was very difficult for people to make sense of the diverse health care needs and the several providers, especially since most of us had pretty limited experience with the medical system before this.

Identifying Symptoms of AIDS

Hughes: Did you talk to Mark about why he had not done something sooner about the symptoms he was experiencing?

Helquist: I'm not sure why he didn't check them out, because he said that he was feeling so much weaker, that he was losing hair, that

¹ Donald I. Abrams, M.D., in The AIDS Epidemic in San Francisco: The Medical Response, 1981-1984, Volume II, Regional Oral History Office, The Bancroft Library, University of California, Berkeley, 1996. Hereafter referred to as the AIDS physicians series.

² Dr. Lozada was assistant professor of oral medicine and hospital dentistry in the UCSF School of Dentistry.

over a six-month period, he had lost twenty pounds. And he may have had those monitored by a physician a bit, but there was not a clear connection to what we now call AIDS.

Hughes: He wasn't thinking AIDS, or at least not admitting to it?

Helquist: Somewhere in between, I would think.

Hughes: Was there enough information out there that a person, such as Mark, who didn't have a medical background, would know that KS, weight loss, and so on could mean that something was really wrong?

Helquist: I think the awareness was of these lesions: "KS lesions--we need to look for those, and I hear there's some pneumonia connected with it." But there wasn't any comprehension of HIV disease as we understand it today, and weight loss wouldn't necessarily have been linked to it, nor would hair loss or fatigue or oral thrush. So I think he probably partly took the approach that there were all these things going on in his body, and they were distressing. But he had a very active life in the community, and he was involved in lots of different things such as politics, the lesbian/gay synagogue, and his own business ventures. I think he sort of kept on with that busy schedule with all this in the back of his mind.

The Kaposi's Sarcoma Clinic, UCSF

Accompanying Mark

Hughes: Well, talk, of your perception of the KS Clinic and how it was perceived by the community.

Helquist: I don't know if I had read much about it before my first visit there. But I remember accompanying Mark on one of his visits, and this must have been the first couple of days of December, 1982. I remember sitting out in the hallway of the Ambulatory Care Clinic with him, waiting for the nurse to come. The nurse came out, who happened to be Helen Schietinger, and Mark introduced her. [laughs] I think he said, "I'd like you to meet my vampire. All she does is take blood from me." [laughter]

Hughes: So he'd obviously been to the clinic before.

Helquist: Yes, he'd been there before, and was just starting to get into the whole medical and research system of what was involved.

Hughes: Did you actually go with him from his home to the clinic?

Helquist: Yes.

Hughes: What did he think about going to the clinic?

Helquist: Well, I think there was such a huge mix of emotions. He talks about it in his journal, which isn't so much focused on the clinic, but just everything going on in his life. Sometimes he really wanted to play for the sympathy, and sometimes he really wanted to go for the drama. And at other times, he was this scared little boy who didn't know what was happening, and having all these people do tests on him. [looks through journal] This is when he saw Don Abrams.

There's one mention in here that was sort of touching about when he went up to either the clinic or the med center. He said he needed to go on a merry-go-round of tests at UC Medical Center, and then in parenthesis he says, "Where the last of Nazi operators devise new tortures for little Jewish boys."
[laughter]

Hughes: Who was he referring to?

Helquist: Anyone who was poking him.

Research on Patients

Hughes: Helen told me that the intake interview, the first interview when one presents oneself at the clinic, was really comprehensive.¹ These early patients were really research subjects as well as patients. They were there of course for diagnosis and whatever treatment was available, but they were also to be studied, to try to find out what was going on.

Helquist: Right.

Hughes: Now, were you and Mark aware of the research dimension, which would explain the massive bloodletting?

¹ See the oral history in this volume with Helen Schietinger.

Helquist: Yes. Well, he had the continual blood-giving, but he also talks about having a colonoscopy, endoscopy, sigmoidoscopy, all these tests which maybe at that point were eventually helpful to him for symptom relief or something, but in retrospect probably had more relevance from the research side. There was also a feeling pretty early on, I think with him and when I was with him, that we don't know much about what this disease is, and research is really necessary. So if this is the way we can contribute, then we'll be part of the research. The notion of patients being their own advocates had barely become present in the gay community. Activism about drug access and general medical care was a few years off.

Hughes: There was no hesitation--

Helquist: No, there wasn't quite the same feeling that developed later, and that is certainly present today, of patients saying, "I'll do this for research, but I'm not willing to do that, and it's my choice. I don't want that procedure again." There wasn't much a sense of that choice. Mark was overwhelmed by the news of his multiple diagnoses, and just kind of did what people told him to do, which was probably appropriate.

Hughes: What was the actual procedure in the clinic?

Helquist: I think I may have waited for Mark outside, so I think I really wasn't in the clinic long enough to know.

Hughes: Were you included in any of the discussions with the physicians? Or Helen, or anybody?

Helquist: Not in that very early stage. After awhile, when Mark was hospitalized at SF General, or when he was at the UC Med Center, then I was sort of included. I was his--what? I don't know--one of his monitors of what was going on. In the early '80s it was not very common for a gay man to accompany his partner, the patient, during medical consultations and procedures with physicians and technicians.

Writing about the Medical Aspects of AIDS

Helquist: I guess it was a very fortunate connection in a lot of ways for Mark and me and for the larger community. Here I was wanting to write; here was someone who had a story to tell, and was kind of desperate to tell what was happening. I hadn't come from any medical background whatsoever, and I needed to do my research to

even know what some of these doctors were saying. It got me started in my own medical writing, which in the very early days in the gay press was really very basic. I believed then that it was important for people to know some of the medical jargon of what was being said, and not just talk about "the gay cancer" or "that weird pneumonia." There were specific efforts that I and others made in print of telling people how to pronounce *Pneumocystis*, just kind of getting your tongue over that and getting familiar with it.¹

Hughes: How did you educate yourself?

Helquist: Initially by reading articles, most of which were in the gay press, a lot coming from New York. And then reading what was in the MMWR [Morbidity and Mortality Weekly Report] from CDC, the little bit that was there. I spent a lot of time with a medical dictionary as I was trying to write and explain things. And I began to conduct a lot of library research regarding medical conditions that were known in the literature, even if the link to AIDS hadn't been made yet.

Hughes: Did you have any friends, physicians in the community?

Helquist: Not at that point. I only started to once I started interviewing them, and got to know them, and certainly learned more as a result. In those early days, the physicians were very accessible, and I was able to interview Drs. [Paul A.] Volberding, [Marcus A.] Conant, [Donald I.] Abrams, [Jay A.] Levy, [Constance B.] Wofsy, and others.

Hughes: So you saw your role as an educator?

Helquist: Yes, with my writing, I was. At first, I wasn't really sure what it was, because it was new to me. It was new to be writing and publishing. But clearly, I began to feel more like an educator talking about the different treatments, doing some of the initial research.²

¹ M. Helquist, "To Your Health: What's in a Name?" The Advocate, Los Angeles, August 6, 1985:426.

² M. Helquist, "The Helquist Report," bi-weekly column in The Advocate, 1984-1990.

The Gay Community as a Source of Medical Information

Helquist: One of the interesting things that I think happened in the early days was the fact that so many people in the gay community started doing their own literature research and sending it to all these physicians. Anyone who was recognized for doing AIDS research work, whether it was CDC, NIH [National Institutes of Health], or local doctors, there was this very ambitious trading of information. Because, of course, a lot of these docs didn't have the time to go search some of these things out, and there was just an awful lot of sharing of information. Actually, I guess it was more one-sided. It was the gay community funneling information into the health care system.

Hughes: Give me an example of the sorts of things that you would funnel.

Helquist: Hmm. I guess most of the activity was about treatments.¹ In those days, treatment for AIDS conditions was very new, very fluid. Although there were, of course, established treatments for skin cancers and some lung infections, this new virus put established practices in a very different context. Many of the diseases had seldom been seen in young men, and the many concurrent infections made all treatment approaches more complicated. So a lot of the early collaboration between the gay community and researchers and physicians focused on new treatment possibilities, using existing drugs in a new way, or using alternative or natural therapies.

This was a very dynamic time. Many gay men were regularly sending information to the researchers at the CDC and NIH, as well as to physicians in private practice everywhere in the country. Some early contributions that I'm aware of focused on information about possible gay lifestyle activities that might contribute to an immune system breakdown.² For example, much of the literature review and research about the popularly used "poppers" (amyl nitrate)--used to get a quick high on the dance

¹ M. Helquist, "State of the Science," monthly column, Coming Up!, San Francisco, May 1984-July 1986; Helquist, "To Your Health," bi-weekly column, The Advocate, Los Angeles, 25 June 1984-17 September 1985 (column renamed "The Helquist Report," 1 October 1985-4 June 1990; Helquist, "Therapies Pose Real Dilemma," Philadelphia Gay News, 9 May 1985.

² M. Callan and R. Berkowitz with R. Dworkin, "We Know Who We Are: Two Gay Men Declare War on Promiscuity," New York Native, 8-21 Nov. 1982.

floors or during sex--came from gay health activists.¹ Much of the early work on whether AIDS was an autoimmune response was reported in the gay media of New York and San Francisco.² And there were some ground-breaking efforts regarding the link between AIDS and substance abuse,³ the possible usefulness of a photochemical compound called DNCB as a topical treatment and activator of the immune system.⁴

There were also several false leads promoted by the gay media, primarily from the publisher of the New York Native newspaper. The possible connections between AIDS and the swine flu vaccine, AIDS and syphilis, and many others were strenuously promoted in this newspaper.⁵

Hughes: Now, locally, was it the group at San Francisco General and at the KS Clinic?

Helquist: Yes, locally, there were physicians at SF General (Volberding, Abrams, Wofsy) who listened closely; also, many private practice physicians like Bob Bolan, Wally Krampf, Steve Mehalko, and Steve Follansbee.⁶ The active communication also had several other benefits: researchers became more accustomed to appreciating the input from gay men who weren't health professionals. Several professional relationships and friendships were formed between the physicians and a great number of gay men. This helped set the foundation of cooperation that we are still seeing today.

¹M. Helquist, "To Your Health: Action on Poppers," The Advocate, Los Angeles, 6 August 1985.

²M. Helquist, "The Story They Missed: Autoimmunity and Cyclosporin/DNCB," Coming Up!, San Francisco, Dec. 1985; Helquist, "Autoimmunity and AIDS: Researchers Find New Link," The Advocate, Los Angeles, 21 Jan. 1986.

³M. Helquist, "The Neglected Risk Group: I.V. Drug Users," Coming Up!, San Francisco, Jan. 1985.

⁴M. Helquist, "Legal and Inexpensive Drug Found to Improve Immune System of AIDS Patients," Coming Up!, San Francisco, Oct. 1985; Helquist, "The Helquist Report: New Immune Booster--Both Legal and Inexpensive," The Advocate, Los Angeles, 12 Nov. 1985.

⁵James E. D'Eramo, "Is African Swine Fever Virus the Cause?" New York Native, 23 May 1983; "AIDS and Syphilis," New York Native, 16 Feb. 1987.

⁶ Oral histories in this program with Bolan and Follansbee are in preparation.

Hughes: In the community?

Helquist: Individuals in the community were generally quite willing to work with anyone who could help; we were all in a crisis mode. Also, the organization Bay Area Physicians for Human Rights (BAPHR) was a focal point for all the concerns of the community, both medical and social.

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Hughes: BAPHR was taking a rather active political role as well.

Helquist: Yes, it was. Many physicians--primary care, specialists, and psychiatrists--involved with BAPHR were sought for assistance and guidance, not only by the gay community, but also by government offices and elected officials. And some of the BAPHR members felt quite strongly about the civil liberty issues involved. BAPHR members were very active in the gay bathhouse controversy, fighting general discrimination against their AIDS patients, protecting patients' rights in research studies, and in formally advising the Public Health Department. Not only were many of these doctors struggling with the new medical challenges brought on by AIDS, but they were being drawn into the very contentious world of San Francisco politics.

The Bathhouse Episode, 1983-1984

Physicians Enter City Politics

Helquist: The whole political dimension of the epidemic was coming in, not only the politics of trying to get any federal research money, but the whole politics around the bathhouses here in the city. It was a little unusual, I think, for how much the physicians got pulled into it or walked into it. And a number of them got very bruised by the experience.

Hughes: Well, talk about that.

Helquist: Although physicians were involved in many AIDS political issues, the most troubling and divisive was the gay bathhouse debate. The city government was very much involved, primarily the office of the mayor, Dianne Feinstein, and that of the Director of the Public Health Department [1977-1984], Dr. Mervyn Silverman.¹

¹ See the oral history in this series with Mervyn Silverman, M.D.

Feinstein has a political history of opposing anything sexual;¹ she also had a genuine commitment to preventing the spread of AIDS in her city. She wanted the baths closed, and she used ethically questionable means to make that happen.² Silverman was bucking the pressure from Feinstein's office to close the baths. He consulted with a group of hospital and community physicians about the bath closure issue. This group met regularly and tried to determine what action was necessary for HIV prevention--and for political realities.³

In addition to the politics of government officials, there was also the gay community politics. Many physicians became embroiled in both. And, of course, the fears, the biases, and the ambitions of the physicians added to the overall context of the debate. Some of the physicians were publicly castigated for their positions on the gay baths. The problems were even more difficult for the gay physicians who felt the baths were a link in HIV transmission, but who were also sensitive to the sexual repression inflicted upon gay men historically. Many of these physicians may have been adept with academic political infighting, but they became vulnerable and exposed in the public arena of debate. The criticism and charges of betrayal were difficult for them to take. It was a very charged, very emotional, and very unpleasant time.

Reporting on the Baths

Helquist: I actually did a series in the gay press, in Coming Up! newspaper about the baths.⁴ I guess it was right after Feinstein had, through her agencies, sent private investigators into the baths [fall 1984]. The San Francisco Chronicle or Examiner would only refer to it as "the steamy details." They

¹ M. Helquist, "The Sexual Politics of Dianne Feinstein," Coming Up!, San Francisco, Oct. 1984.

² M. Helquist, "Silverman's Sex Spies Put Private Acts in Public Record," Philadelphia Gay News, 8 Nov. 1984; R. Osmon and M. Helquist, "Behind Feinstein's Police Surveillance of Baths (Analysis)," California Voice, San Francisco, 7-13 June 1984.

³ M. Helquist and R. Osmon, "Bathhouse Controversy: A Frantic Week and Divided Community," Coming Up!, San Francisco, April 1984.

⁴ M. Helquist and R. Osmon, "Sex and the baths: a not-so-secret report," Coming Up!, San Francisco, July 1984.

made it very lurid, but they didn't really tell you what it was that was going on.

So I and my partner, Rick Osmon, decided, "Let's demystify this. Let's go in there and write about what's there." Not only did a lot of the population not really know other than what they thought happened, a lot of lesbians didn't really have an idea. A lot of gay men didn't have an idea. They were either scared or intimidated or not interested. The popular notion of, you go in the door and you walk into an orgy was far from true. A lot of people would point out, you can end up walking for hours up and down the hallways and it wasn't very interesting or exciting. [laughter]

So we went in and we just described people we met, who we talked to, and their notions of safe sex, and how aware they were. We told the clientele what we were doing and why. We guaranteed their anonymity. And actually that particular issue of the newspaper was pretty popular, because I guess there might have been some prurient interest, but also just, Oh, this is what it is. We did a survey of all the baths and sex clubs. I think over a period of eight days, we went somewhere nearly every night, which was really exhausting.

Hughes: And this was before the baths had actually been closed? No decision had been made yet?

Helquist: Yes. But the momentum to close the baths was well underway. And Silverman continued to meet with his community physician advisors (including Volberding, Abrams, and Bolan). There was huge pressure to act. I remember a friend telling me that he was going down the street one day in the civic center and he crossed paths with Don Abrams, who was quite worked up. Abrams frantically shouted, "We've got to do something!" And the something that he and others felt must be done was to close the baths. It had the appeal of being a concrete action in a very fluid and uncertain time.

Helquist's Stance on Closure

Hughes: Did you have a stance on the issue of bathhouse closure?

Helquist: Initially, I did, which was, "Let's not close them; let's use them. Let's use them for education; let's get the message out; let's do STD [sexually transmitted disease] testing in them and all of that." As I started writing about it more, it was

clearer that there were enough opinions and enough emotion out there, and what people really needed was just some reporting, as objective as possible. So then I pulled back to do that. Both around the bathhouses, and then the later controversy about whether to get tested or not. That kind of pulled me into more objective journalism, too.

Randy Shilts's Journalism¹

Helquist: Randy Shilts certainly kept the bathhouse topic top of mind, and deserves credit for that, keeping a focus on it, because much of the sex that occurred in bathhouses definitely was a contributing factor to the transmission of the disease. It was much debated whether you could change the behavior or if you had to change the facilities. And, as objective as he tried to be, I think he also faltered and revealed his own personal feelings about it, because at times, I think frankly, he manipulated some of the news.

In late 1983, the city health department issued a report about STD rates in the city among gay men, and there was a relatively small jump in cases of rectal gonorrhea. Randy used that, and it ended up coming out sounding like there was this big, major increase, and that the bathhouses were the cause.

Hughes: Scare techniques.

Helquist: Yes.

Hughes: How do you feel about his reporting of the epidemic?

Helquist: Well, I know that I'm biased about it, partly because of this inaccurate and egotistic stance that Shilts took that he was the lone reporter on AIDS in San Francisco. I was one of those people whom he was ignoring. And it wasn't just people writing in the gay press; it was people like Jim Bunn, who was one of the primary news reporters for one of the local TV stations, KPIX. He was kind of ignored out of the picture, too. So I felt some resentment for him related to being kind of ignored for the work that I and others were doing. So that feeling colors my sense of Randy's reporting. And there was a kind of personality clash, although Randy and I didn't have too much

¹ Randy Shilts is the author of And the Band Played On: Politics, People and the AIDS Epidemic, New York, Penguin Books, 1988.

contact. People who knew us let it be known that now and then we each made a crack or two about the other.

I think Shilts's book, especially, was very good for providing a large picture of the epidemic and making it real for people. Really, it did that.

Hughes: Do you think the fact that he slanted his reporting pushed you to the other side?

Helquist: Yes, I think that was part of it; there were enough very strong opinions being voiced around the baths. And then there was the later incident in Randy's book about identifying a supposed patient, Patient Zero, which was a great marketing tactic for the book.¹ The person he describes [Gaetan Dugas] was real, as were the circumstances of having sex with lots of men and being a flight steward. But a Patient Zero? [laughs] No. The federal health authorities afterwards said, "No. That didn't happen. It's not really possible to say this is where the epidemic started."

Hughes: Well, now it's quite clear that it didn't start there.

Helquist: Of course. And the whole notion that here's the gay journalist (Shilts) pointing out the supposed gay man "responsible" for the epidemic was just too much for many people to stomach. It was crass, inflammatory, and very poor journalism. It's not like we didn't want Shilts to tell the truth, even if it put some gay people in a bad light. But we certainly did not want to be scapegoated because of a fabricated theory that seemed designed to help market the book.

So a lot of people remained alienated from the popularity of Randy Shilts' AIDS work. His later book on gays in the military² ameliorated some of the bad feeling, but for many in the community, Shilts remained somewhat of a pariah.

¹ Ibid.

² R. Shilts, Conduct Unbecoming: Gays and Lesbians in the U.S. Military (New York: St. Martin's Press, 1993).

AIDS Education

Behavior Change

Helquist: A number of the doctors got involved early on helping people develop the brochures or the posters, the posters that would show up in bars and in bathhouses.

Hughes: How effective was that campaign?

Helquist: In the baths?

Hughes: Yes, or anywhere. Did people really take note and think about changing their behavior?

Helquist: Well, since that time, I've worked a lot in behavior change. I wasn't very knowledgeable of it then. But there's generally a feeling that there's a small percentage of a population who might be called "early adopters," where they'll see a message and just rationally, intellectually say, "This is it; this is the problem; I have to change what I'm doing." Not many of us do that, [laughter] but some do that. So I think that those early campaigns were effective to that degree, for some people more than others.

Probably for most people, it was more of just establishing a counterview and a seeping awareness and acceptance that this epidemic was going on and it was serious. But I'm impatient with people who say today those campaigns didn't do anything; we thought education was going to do it all. Well, maybe the people saying that were naive enough to think that education would do it all. Anyone who has been involved in behavior change, or really thought about it very much, would say, "No, they're not going to change everything with awareness alone."

Public Health vs. Gay Rights

Hughes: The issues of privacy and gay rights overlay this primary problem of behavior change. The bathhouse issue was framed as public health needs versus individual liberties and gay rights. It was an either/or perception. Was that the way people were seeing it?

Helquist: We had a gay population here which was older, meaning maybe in their twenties or thirties rather than their adolescence, discovering and expressing their sexuality. They hadn't gone through some of the early phases that others might in high school. And there was an exuberance about that, and a personal freedom of saying, "More than I thought, I'm okay. I'm a sexual person, and it's okay." And none of us had heard that sentiment much from anyone before. So there was sort of a celebration of spirit.

In the gay men's community of the seventies and early eighties, there was a lot of encouragement for exploring your sexuality and getting out of the closet. In the midst of this liberation arrives a deadly disease apparently spread via sex. Many men felt threatened that their newfound openness would be once again restricted. And there were certainly plenty of signs then, as there are today, of groups who wanted to stifle the gay population. We barely got a few moments of breathing and living in freedom before AIDS changed everything about our lives.

Our experience told us that the disease was not hitting gay men because they were gay; clearly, there was a link to some kind of external disease mechanism. Some gay people were already politically astute and quick enough to recognize how this disease could be used against us. These activists resisted the shutting down of buildings, of community institutions, as well as attempts to shut down freedom of expression. Many of this group were often adamant and absolute in their convictions, resisting even a discussion of changing behavior to protect against disease.

There was another faction in the gay community saying, "Let's look more at what these bathhouses are and what function they serve."¹ Yes, they are obviously there for sex. But they're also a safe place to be, off the street; no one's going to beat you up; no one's going to call you names. If you're cruising someone, you don't have to worry if they're really a cop, or that they're going to rob you and kill you or whatever. And some of the nicer bathhouses were kind of social centers, for watching TV or just relaxing.

And they were also one of the few places where some of the population could be reached. Whether they were bisexual men or closeted men or out-of-towners or whatever, any other part of the AIDS education campaign wouldn't have reached them.

¹ A. Berube. "The history of the gay bathhouses." Coming Up!, San Francisco, December, 1984.

Hughes: So the posters were right there in the bathhouses?

Helquist: They were right there, yes.

Safer Sex Education

Hughes: There's been criticism that the bathhouses were not an appropriate place for education.

Helquist: What? Instead of just telling people to stop? Where, in classrooms and newspapers? This was a deadly disease, and some people were talking about "appropriateness." You go where the people are, period. That includes the baths, the streets, the schools, the media.

Hughes: If you go into a bathhouse, it's not usually to be educated about safe sex.

Helquist: And if you go into a grocery store, it's not usually to be educated about nutrition. But that doesn't mean it can't happen. It doesn't mean that people won't learn something or think about making some changes that they hadn't anticipated. "Education" is often talked about as if it were a very static, manageable even occurring in only certain places. Well, it's not.

Remember that safe sex was a very new notion. Perhaps the term could have been coined to counteract unwanted pregnancy in other health campaigns, but it wasn't. At first, "safe sex" was more narrowly focused: it was all about what you should not do.¹ Safe sex had a negative connotation; it was a grudging change, and there were suspicions about who was defining what safe sex meant.

It's taken quite awhile for the term to become more positive and affirming. The newer message says, "You can still be sexual, you can still express yourself, but there are some new things you should add to your sexual experience." Much more positive. And all originating in the gay community. One of the

¹ M. Helquist, "Safe Sex--Guidelines that Could Save Your Life," The Advocate, Los Angeles, 6 August 1985; Helquist, "Safe Sex--Guidelines that Could Save Your Life," in Gay Life: Leisure, Love and Living for the Contemporary Gay Male, ed. by E. Rofes (Garden City, NY: Doubleday & Co., 1986).

most influential brochures emphasizing this approach was developed by the Harvey Milk Gay Democratic Club in 1983, I believe. The brochure called "Can We Talk?," after the then-popular stand-up comedy routine of Joan Rivers, was simple and straightforward, gay and sex positive, and used the casual language that gay men used. It was an immediate success, and became a model among the gay population of U.S., Canada, Europe, Australia, and several developing countries.

This brochure helped set a new tone for AIDS education. So, when men went into the baths and sex clubs and saw posters with these new messages, the effect was in contrast to all of the negativity and blame about AIDS that they experienced outside. There was also an effort at this time to romanticize and eroticize the notion of safe sex. Dating was promoted with a romantic theme, rather than just quick sex, and using condoms and other products were sold with an erotic theme, rather than a simple focus on disease.¹

AIDS and the Gay Community

Political Divisiveness and Demoralization

Hughes: Can you say something about the impact of the epidemic on the gay community here? Some of its political divisiveness is certainly highlighted in Shilts' book. What more is there to that story?

Helquist: Well, there's certainly that, what I would see as sort of the downside, the political divisiveness, which was going on related to other areas of life, other political things. It was a period when the gay Democratic clubs were coming into their own and competing with each other, so there was strife among politically active members of the community anyway. Not all gay people are like this, but a lot who were prominent were very articulate, had very strong opinions, and they knew how to use the media to get their opinions covered and spread. So that was prime for any controversy that came along.

I think the other negative effect certainly was a demoralization, was feeling stigmatized in a different way all of a sudden. All of those things going on had an impact. Plus seeing the numbers of AIDS cases increase.

¹ Helquist edited and rewrote much of this paragraph.

In those days, it was early enough in the epidemic that memorial services for some gay men were held on Castro Street. When Bobbi Campbell died [August 15, 1984], Castro and 18th were closed and a stage was put up, and his parents and friends talked about him. It's just not something that would be done now after thousands of people in the city have died of AIDS.

But it was interesting, too, that there was a very energizing element to having this new disease in our midst. It was partly the drama of it, partly the excitement of something new and something that we could work on, the excitement for a lot of people of coming into careers, not just the physicians and the nurses, but journalists, activists, politicians--lots of different people who were needed, but nevertheless advanced in their careers as a result.

Lesbian Involvement

Helquist: I think of the most striking positive things that occurred, one was the involvement of women in AIDS care and AIDS activism, lesbians in particular. Prior to this, like in the early 1980s,¹ there was much more talk and expression of lesbian separatism. Many lesbians wanted to be separate from men, and gay men. Gay males, gay white males primarily, were those in power, those who predominated in all sorts of social and political functions.

It's not accurate to say that most gay men didn't like women. But there was enough feeling of resistance or anger or whatever coming from their backgrounds, that you could feel that that was one of the elements, and there was a real separation. This was the time, late seventies and early eighties, when the Gay Pride Day and March was just that: it was called gay pride.² It took a few more years before things loosened up a bit so events and groups were renamed, e.g. gay and lesbian pride, and gay and lesbian democratic club.

I think with AIDS, a number of dynamics shifted. Partly there was a shift to more prominence of people in the health

¹ Lesbians joined gay men in great numbers to oppose the Anita Bryant crusade (1977), and the Briggs Initiative against gay teachers (1978).

² The event changed its name in 1978 to the Lesbian/Gay Freedom Day March and Celebration.

care field, whether in direct medical care or in helping professions, like social workers or the Shanti organization. So leadership in the community was broadened. There were more voices to be heard.¹ And it became very clear to gay men that women had many talents and abilities that men had never developed in themselves. So here they were, responding as leaders, a caring response, knowing how to deal with the medical system, or being willing to go into it. It started blurring some of the boundaries between gay men and lesbians, and appreciation grew incredibly for the women in the community who were there and who were doing so much.

Early on, there probably was some understandable resentment in the lesbian community about, "Sure, we're sorry this epidemic is happening, but we have our own issues, and where have you been for us?" This attitude shifted, not because gay men adopted lesbian issues as their own, rather lesbians realized that all of our rights were threatened because of the negative response to AIDS.

Hughes: Has the epidemic served to pull the two elements together?

Helquist: Yes, it definitely did that. Then with the toll of gay men being so great here--what is it, 15,000 having died by now?--a lot of the natural leaders or those in place, people like Bill Kraus,² have died. So maybe their assistants who were women, or their colleagues who were not so prominent, were able to move into the void.

So there was an appreciation for what women were doing; there was a little broadening; there were men beginning to see that maybe their lives were a little too limited the way they were living them, as well as political changes where women came into more prominence.

Hughes: And what about simple friendships? There's nothing like proximity in working for a cause.

Helquist: Yes, very much so. I had a few women friends before AIDS started using up so much of my time, but I developed many more

¹ M. Helquist, "Facing the Gay Health Crisis: Coping with AIDS in our Community," Coming Up!, San Francisco, February 1983.

² Bill Kraus was active in the Harvey Milk Lesbian and Gay Democratic Club, served as assistant to Supervisor Harvey Britt, and to U.S. congressional representatives Philip and Sala Burton.

friendships with women as a result of having more contact with health care workers and politicians and others who were involved. So the bonds just really shifted and changed a lot. And it was kind of a relief that AIDS wasn't hitting at that time men and women, gay men and lesbians, for those who may have been concerned about, What's going to happen to our population? And early on when we didn't know what the toll was going to be. I think early on, people thought, "This won't kill every gay man, but it may get close to that."

Hughes: It could be turned the other way around: Here I am, a gay man, who's had enough problems with society so far. You're a gay woman; why are you spared?

Helquist: Yes, I suppose some men felt that way, but I don't believe there was a predominant resentment toward lesbians about AIDS.

The Kaposi's Sarcoma Research and Education Foundation

History

Helquist: The KS Clinic made sense because it had an early history in dermatology. Marc Conant was a dermatologist, and here were lesions on the skin, so clinically the connection made sense. But the fund-raising organization was the KS [Kaposi's Sarcoma Research and Education] Foundation, and then after awhile, it was expanded to the KS and AIDS Foundation. There was the KS Foundation, KS and AIDS Foundation [San Francisco AIDS/KS Foundation], and then some of the politics split it off into the local foundation [San Francisco AIDS Foundation] and the AIDS National Research and Education Foundation.

It was just a storefront effort where people were volunteering, sending out pamphlets, trying to organize some town hall meetings, very small offices to begin with, very few resources. And then gradually it built up, and I guess it maybe moved four or five times around town into larger and larger offices.

Hughes: And it created a hotline, right?

Helquist: And the hotline, that started early on [1982]. A friend of mine was the first director of the KS Foundation, Rick Crane. It was a very difficult time. Not only were people who maybe didn't

have the experience brought into the organization, but then it kept changing and evolving. For a long time having activists involved in leading the organization was needed and appropriate, but at some point as more money came in and as things got more complicated, you needed people with training and professionalism. This shift in staffing was difficult, and, at the time, it felt like there was just nonstop controversy one way or another, plus this medical crisis.

Hughes: Was the main function of the KS Foundation in those early days education?

Helquist: Yes, definitely, but with an emphasis on AIDS awareness, acknowledging the health problem.

Hughes: How effective was that?

Helquist: I think probably very effective for what could have been done so early on, both because of limited resources, and no one else was working on this. So yes, it was grassroots and it was very low-scale media work, as we would look at it now. But it was the only thing that was going on pretty much during the period of 1981 to 1984. There was this foundation, and there was the Gay Men's Health Crisis [GMHC] in New York, and not many other AIDS organizations had started in the country. And today, of course, there are hundreds of community-based AIDS organizations.

Rivalry with the Gay Men's Health Crisis

Hughes: Was there any communication between the coasts?

Helquist: Yes, there was, since there was generally a lot of gay travel between the coasts. And, not surprisingly, early on there was a rivalry between GMHC in New York and everyone else, including the AIDS Foundation here. GMHC was founded first, which even today, they will not hesitate to tell you.¹ New York City can always put in more money than San Francisco for benefits, and much of the early GMHC efforts involved fundraising, and they

¹ GMHC began meeting in New York City in August 1981. (AID [sic]: Acquired Immune Deficiency. GMHC Newsletter, #1, July 1982, donation to interviewer by Helen Schietinger.) By March 1982, a "Kaposi's Sarcoma Fund" had been established with a donation from Marcus Conant. (Hollis Gray to Marcus A. Conant, March 30, 1982, Conant's Kaposi's Sarcoma Notebook, March-December, 1982. Hereafter, KSN.)

were very successful. Many gay people contributed to the fight against AIDS in New York by going to benefits, donating money, and coordinating efforts with other service organizations. However, in San Francisco, money was not so available although we did mount benefits. The emphasis here was more on volunteering and community involvement, volunteering for office work, materials distribution, emergency services, hotline services, and overall community awareness.

As it became more clear that AIDS was going to be with us for quite some time, people active in the struggle began to think of a national AIDS organization. After all, we were all familiar with disease and health-focused organizations like the American Cancer Society and the March of Dimes. At the time, it seemed that a national AIDS group would help focus efforts and coordinate fundraising. As a result, there was a rivalry and some contention in 1982 until 1984 about who would form such a national group. GMHC proposed that they simply become national, not focus just on Manhattan, and the San Francisco AIDS Foundation (SFAF) was considering exactly the same role for themselves. In San Francisco this plan became more complicated when some of the supporters of the early local foundation (including Dr. Marc Conant of UCSF) decided to form yet another AIDS organization, the AIDS National Research and Education Foundation. A separate board of directors, paid executive director and staff, and program goals were established. The New Yorkers found this action to be presumptuous and resisted any plan for the new organization to develop local affiliates.

The national foundation soon faltered [March 1984] due to poor management, lack of funds, and the fact that groups were already forming independently in other cities to address their own needs. Thus major organizations soon developed in Los Angeles (AIDS Project Los Angeles), Atlanta (AIDS Atlanta), Seattle (Northwest AIDS Foundation) among many, many others.

"Person with AIDS"

Helquist: One element that I am aware of through Mark Feldman is the whole naming issue. Giving names to what's happening is important, and from the best that I can tell, through my being there and through my research and writing, Mark was the first to coin the term "person with AIDS." Clearly, the description until then was "AIDS victim," which still continues today in some of the media.

At one point, I think it was the Denver conference of gay/lesbian health workers, the Fifth Annual National Lesbian /Gay Health Conference, that was in early June of '83--people

came from all over the country, but there was a big contingent from New York, a big contingent from San Francisco, and many people with AIDS came. The San Francisco contingent was more adamant about saying, "Look, we need to refer to ourselves as people with AIDS." The New Yorkers had certainly gotten beyond the point, if they were ever there, of thinking of victims, but they were settled on saying, "We are patients with AIDS; we're AIDS patients." Still medicalized. So there was a little bit of a clash, although "person with AIDS" came out as the more popular and it predominated.

The National Gay/Lesbian Health Association

Hughes: What did become the early national spokes-agency for AIDS?

Helquist: There wasn't one central organizational voice. Soon the several AIDS groups started working together among themselves, informally. These organizations were quickly overwhelmed with their own local patient service and care needs, and the AIDS education programs. There really wasn't the time or energy to address local needs and to assume national leadership, although GMHC and SFAF remained then, as they are today, predominant voices. In September 1985, a national fundraising organization, The American Federation of AIDS Research (AmFAR) was formed and continues to raise grants and funds for AIDS research. Dr. Mervyn Silverman later became the executive director of AmFAR.¹

One other organization, the National Gay Health Education Foundation (NGHEF), did provide leadership for the many gay health care advocates and providers. The association convened national meetings about AIDS two years before (1983) the federal government ever mounted its own conferences.²

Hughes: The association existed before AIDS?

Helquist: Yes. It initially focused on STD [sexually transmitted disease] work and concerns--STDs showing up in the gay populations in the 1970s and early 1980s. Yes, a lot of early gay and lesbian physicians, nurses, epidemiologists, and behavioral researchers

¹ M. Helquist, "Foundation for AIDS research will be started," Oakland Tribune, 25 Sept. 1985.

² The First International Conference on AIDS co-sponsored by the federal government was convened in Atlanta in June of 1985.

got started there, and fortunately were somewhat poised to then broaden the perspective into including AIDS in their focus.

The Shanti Project

Hughes: What about Shanti?

Helquist: Well, Shanti certainly became a national model and leader, a one-of-a-kind organization in those early days. Certainly they started out very small, first meeting in Jim Geary's living room.

Hughes: Shanti existed before the epidemic, is that not true?

Helquist: Shanti was an organization before the epidemic. Charles Garfield had established Shanti, and I think Jim Geary was involved with Shanti work then, which focused primarily on end-stage cancer support work. It wasn't really a hospice focus, but certainly it was concerned with people who were dying. They were based in the East Bay. Then AIDS appeared, and Shanti shifted its focus to include people with AIDS. Bobbi Campbell became sort of a spokesperson for Shanti, and the organization moved to San Francisco, and then started growing rapidly.

You are probably aware of some of the early development and criticisms of the Shanti approach. First of all, it got established and its approach seemed just right. Here's what people with AIDS need; we need some emotional support. The whole notion was kind of unfamiliar to us. There was an emphasis on dying well, coming to terms with death and dying. There were death simulation exercises or visualizations, where this whole group of people would be in a room sort of like a gymnasium, and you'd be lying on your back on the floor. Someone would guide you through the exercise, talking about, "Now imagine this; now imagine this." It was a very powerful experience.¹

It seems like it was mostly appropriate for the time. That is what was happening: people were dying. It was difficult dying, so here was a response to it. Only later, partly because there were management excesses at Shanti, and there got to be a few personalities that weren't good for the organization, people

¹ M. Helquist, "AIDS workshop mixes coping, hoping--Part one," The Sentinel, San Francisco, 31 March 1983.

started objecting and saying, "Shouldn't we be focusing on living? Isn't there something to fight here?" So there was just constant evolution.

The San Francisco Model of Comprehensive AIDS Care

Helquist: Shanti certainly did become the model for an integrated hospital, community, service organization approach to service delivery. It was an important part of the San Francisco model of comprehensive AIDS care, and it became very common for people from all over the world to traipse into town, go to the KS Clinic, go to Shanti, go to the AIDS Foundation--emissaries from Europe, not so much from Asia yet.

Which also was energizing for people. I mean, here were people from all over the world coming to us to see what we were doing. It was not like we had some grand plan; we just tried to do what we could. Someone all of a sudden called it the San Francisco model.

Hughes: Why San Francisco rather than New York?

Helquist: I haven't ever lived in New York, so it's an outsider's perspective, but my thinking was always that things were much more fractionalized in New York. There was more tension between groups and individuals; there was more infighting. And people were more closeted in New York than they were here. Gay people were certainly active and known to be gay in the social world in New York, but professionally, they tended to be more closeted, so it was more difficult for them to step forward and publicly support an effort to stop a disease, one that was linked so closely to homosexuality.

Plus everything was so much larger scale in New York that I think the notion of community-building would have been much harder in such an intense, urban environment with all the other stresses, the poverty and whatever else was going on. San Francisco felt more like a little protected world where we could do what we wanted to, but it wasn't so big that we couldn't get a handle on it.

And it seemed like the political structure was more accessible here than in New York, that there was some beginning feeling of gay power through numbers of gay voters. But also gay people had permeated every profession, every walk of life here, and were relatively open about it, and with AIDS they

became even more open. So AIDS touched more of San Francisco--gay and straight; so it had more impact.

AIDS Medicine Moves to San Francisco General

Hughes: Why did the focus of AIDS medicine shift to San Francisco General?

Helquist: There was the establishment of the KS Clinic. People who were aware of some of the developments and politics on the inside were aware that, Okay, here was one physician, Dr. Conant, who was very involved, but setting up his little empire--maybe that's too harsh--but setting up his focal point. Then there got to be a shift to San Francisco General to oncologists. And then kind of a jockeying for position: where should the focus be for AIDS medicine. And I'm sure, from UC's perspective, where should the money go?

You don't get a sense that there was much support at UC for being a leader in any of this AIDS work. They responded medically with the clinic and, obviously, the professions were there to respond, but not in any particularly organized or official way until later.

Hughes: Did it matter to the community where AIDS medicine was? Did people have any feelings about its shift to the General, which as a county hospital dealt with a very different patient population? That's where charity patients were seen; the whole edifice is very different from UCSF.¹

Helquist: Well, I think there was a range of reactions to it. On one hand, some people aware of health care dynamics realized that we in San Francisco were very fortunate that San Francisco General was there as the county hospital, because people with AIDS could get care there. There wasn't such a financial burden. Coincidentally sort of, these AIDS experts also were there. So that was a real plus, and people recognized that.

Early on, I suppose, people were more open to going to the General if that's the only place they could go. I think it

¹ Technically, SFGH is part of UCSF, since it is jointly administered by the university and the city. However, in common parlance, UCSF usually means the Parnassus Avenue campus. SFGH personnel might disagree. See, for example, the oral history with Merle A. Sande.

didn't take too long before people realized, I'd rather go to somewhere like UC. I mean, those who knew they could afford it, where it was an option. Or they'd rather go to a community hospital like Davies Medical Center or California Pacific Medical Center.

Hughes: Was that a status thing, or was it the feeling that you got better care at these other places?

Helquist: I think the notion was that at the General, the most advanced AIDS care, what there was, was happening there, but that institutionally, the surroundings were much more pleasant at lots of different places. But this was also a population which wasn't experienced with going to the hospital. Since most gay people here didn't have their biological families nearby, they weren't even going to hospitals to visit aging parents or aunts and uncles.

Referrals to AIDS Physicians

Hughes: That's an interesting point. I imagine eventually it was common knowledge that if you had symptoms which were recognized to be prognostic of AIDS, that you would go to certain physicians. But in the early days of the epidemic, that wouldn't have been obvious. How did people find the health care providers that knew about AIDS?

Helquist: Well, certainly word of mouth was very effective. There were gay and lesbian physicians in practice, and maybe because there was this epidemic of STDs prior to AIDS, those patients who were prone to get the STDs were already connected with a physician. I read somewhere that the old VD clinic is now the site of the new San Francisco Museum of Modern Art. [laughs]

Hughes: Is that the 17th Street health center?

Helquist: No, there was a specific VD clinic where you went for gonorrhea, syphilis, whatever. People either went there, or to some of the neighborhood health clinics, or maybe had their own private physician for general checkups. So there was some foundation, and then I'm sure a movement to different docs who seemed better informed about AIDS. This was still a small world, both San Francisco and the gay community in it, and an inquiry like "Who do you go to for AIDS?" could easily be answered by the AIDS hotline, gay clinic staff, and sometimes, by friends.

Hughes: Yes, it wouldn't be difficult to get the information.

Helquist: Yes.

Psychosocial Support

Hughes: Were Mark Feldman's expectations when he went to the clinic strictly to get medical care, or did he and others look upon it as a place where one could get information about the support system? Namely, what do I do when I walk out of this clinic? Who takes care of me? Do I go back to my community physician, or am I totally reliant on the clinic physicians? What do I do if I don't have anybody to take care of me when I really get ill?

Helquist: Well, there just was very little established. There wasn't experience with the system. I presume there was a social worker at the hospital who would organize your care after you left the clinic, but it wasn't that there was a lot of understanding that that's how it worked. I think people just happened upon the other resources, or heard about them, but there wasn't a patient advocate or any impetus for telling people, "This is how you can deal with it." Although some physicians, nurses, and other staff provided considerable informal information and advice.

Hughes: Helen Schietinger took on some of those responsibilities, but there was a limit to what one person could do. She certainly was aware, from what she told me in the interviews, that the problems were far from just medical, that there were psychological needs, there were simple housing needs, and the whole structure of complicated support had to be built up. It took time.

Helquist: It had to be developed. And of course, this was also in the context of hysteria around AIDS. Why would we assume that organizations and care providers would just say, "Sure, we'll welcome you with open arms"? Nursing homes took forever before they'd accept AIDS patients, and they probably aren't accepting many now. And of course, there was also the hesitancy of people identifying themselves: "I have AIDS. What can you do for me?" So there were lots of problems.

Hughes: A name that crops up in the early history is that of Paul Dague. He was the psychologist who volunteered his time early on in the KS Clinic.

Helquist: Right. I don't remember his involvement with the clinic. I met him and talked to him some; I wasn't close to him. But I know that his having AIDS and then his being open about it, and his dying of AIDS, had a pretty large impact on the professional gay community. But that's all I'm really aware of with him.

Hughes: Did counseling of some kind become more or less a standard part of the treatment protocol?

Helquist: Yes. It became part of the San Francisco model. We thought that this element was important, and we started talking about the psychosocial impact of AIDS. Shanti originally played a major role in that, and then a number of mental health professionals developed what's now the UCSF AIDS Health Project.

Hughes: With which you were associated.

Helquist: I had been involved with several organizations at first: developing AIDS education materials for the AIDS foundation, participating and then training at Shanti workshops, developing promotional materials for San Francisco Hospice. But my greatest long-term involvement has been with the UCSF AIDS Health Project, beginning in 1985 and continuing today. In '85, we developed a monthly newsletter called "FOCUS: A Guide to AIDS Research," that examined various mental health concerns and conditions related to AIDS. "FOCUS" continues today, and it has an international readership.

Thank God there were gay people in those mental health professions at that time, and willing to get involved. It saved a lot of time.

Hughes: Much of this work was done on a strictly volunteer basis.

Helquist: Yes.

Hughes: That was true of some of the clinic staff, as well. There were community physicians who volunteered their time; came every week to be in the clinic.

Helquist: Right. And a critical element again is with gay people being open and in so many parts of the city government and elsewhere, it was easier to pull whatever money there was out of San Francisco. And people like [Mayor Dianne] Feinstein and others were sympathetic and were trying to help.

Hughes: And, there was a city budget surplus as well.

Helquist: Yes.

Fear of Infection

Hughes: How did you deal with fear?

Helquist: I don't remember a lot of fear. I don't remember a lot of fear being around Mark, and there was intimate contact. Mark and I evolved into partners and lovers. Whenever we were sexual, it was like safe sex before the term was coined. But AIDS happened very quickly for him. He was diagnosed and then died seven months later, so the relationship was intense and compressed in that way.

Sometimes when I would spend the night with Mark, friends would say, "Well, maybe it's airborne. Aren't you concerned about his breathing on you, much less touching dishes or whatever?" And I think maybe I was lucky to be involved in the human component so intensely and quickly that I was just there for him. And I don't mean that as complete selfless giving; I was there, he was someone I cared about, and it seemed like there was something that I could do. It's not as if there were any indications that casual transmission did occur. It's just that you weren't really sure.

Once Mark died, my involvement with AIDS only increased and continued (1983-1993). At some point, working with AIDS became a job, somewhat like any other job. It had a daily pattern of expectations and demands. There were clients, and colleagues, and supervisors. AIDS work was becoming normalized for me and many others. I think one of the benefits of the process for me was that "AIDS the job" diluted "AIDS the personal threat." I could be engaged in my work but I could also be detached emotionally at times. Today I realize that during that early period, I used my AIDS work as a defense against taking a close personal look at my fears.

I learned that I was seropositive in spring of 1986. Clearly it was a blow to find this out. I'd expected to be seropositive, but up until the moment when my doctor, Bob Bolan, gave the results, I had held onto some hope that I would be wrong. I don't remember an acute symptom phase after seroconverting, but then we weren't alerted to that possibility. After recovering from the initial shock of discovery, I didn't

focus very much on my own HIV status for years. I was very busy with work, so I really didn't focus on it too much.

I think I didn't really experience fear very much until the last few years. In 1991 and 1992, my T cells began dropping significantly every three months that I was tested. I heard the clock ticking louder, and I knew that if I were to get sick, I wanted it to be in San Francisco and not in Washington, D.C. So my partner and I relocated here (1992), bringing our jobs with us. Then in 1993 my T-cell count dropped below 200, the recently instated number signifying an AIDS diagnosis. That was sobering; the word "AIDS" was now defining my life in frightening ways.

I was looking in Mark Feldman's journal and seeing his entries of 1982 and thinking, twelve or thirteen years ago? Is that possible? I was really there with him then? For some of us, most of our professional lives have centered on working with AIDS.

The Ms Magazine Article

Helquist: I had one little anecdote about Helen [Schietinger]. I wrote the article about the KS Clinic, and that was fine.¹ It went well, and we did it well, and I was getting to know Helen.

I also wanted to both spread the word more and stretch a little bit more professionally. I'm not sure exactly why I thought that I could write something for Ms magazine. I don't think they had really had anything about AIDS before this article. At one point, I saw some of their statistics that said of all the articles Ms had published up to that time, something like 5 or 6 percent were written by men--reasonable enough. But I don't know why I thought this magazine was a possibility, other than I knew Helen and other women were playing an important role in the epidemic. So why shouldn't that be highlighted?

So I sent off an inquiry to Ms, and they were interested enough to say, "Get started and see what happens." Helen and I started the interview process, and at some point, the question came up, Well, do I want to be Helen Schietinger, nurse at the

¹ M. Helquist, "What to expect at the KS Clinic," Coming Up! March 1983.

KS Clinic, period, or do I also want to be a lesbian health care provider? And we went back and forth and back and forth, and I think finally Helen just got tired of having to think about it, and she said, "Oh, what the hell, just put it in there that I'm a lesbian." There was a lot of energy around it, but finally she said, "Well, just do it." So I finished the article and sent it in, and that feminist publication deleted the reference to her being a lesbian. [laughing]

I remember when the question of coming out was an issue for Angie Lewis,¹ and she was in an established, responsible position as a nurse at SFGH. The point came where she just felt like she needed to make a personal and professional choice to not hide a very basic part of her life. I felt great admiration and inspiration for her openness.

Characteristics of San Francisco Hospitals Providing AIDS Care

Ward 5B

Hughes: Did you have any particular insight into AIDS care at San Francisco General?

Helquist: My contact was mostly through a few people who were patients, who were hospitalized I guess even before the AIDS ward was established. Mark Feldman was hospitalized at General once, and I don't remember 5A or 5B being there at the time.

Hughes: It was 5B first, which opened in July 1983.²

Helquist: Yes, so he was there prior to that. Then I started interviewing Volberding and others, so I got to be more aware of what was happening.³

¹ See the oral history with Lewis in this series.

² Gene Ayres. S.F. hospital open's nation's first AIDS special care unit. San Francisco Chronicle, July 26, 1983. The unit, originally located on ward 5B, later moved to 5A.

³ M. Helquist, "Condoms Block Spread of AIDS Virus, Study Finds," Interview with Dr. Marcus Conant, American Medical News, Chicago, 10 January 1986; Helquist, "Interview with AIDS MD expert Abrams," California Voice, San Francisco, 3 May 1984; Helquist, "Interview with Dr. David Werdegart, New Health Director," Coming Up!, San Francisco, January 1985.

Discrimination

Hughes: In Mark's case, was there any problem with treatment before he was on a ward dedicated to AIDS? There was a lot of fear, from what I understand, amongst the hospital staff.

Helquist: I don't think that he encountered very much. He had the one hospitalization there, but mostly he was at Davies, and died at Davies (on June 2, 1983). By that time--it was still '83--there were enough people who were willing to be involved in AIDS care that it seemed sort of the norm, and there weren't so many incidents of discrimination. But I'm sure there were many that I didn't hear about.

Hospitals as Social Centers

Helquist: You know, it's an interesting thing about the Davies center and General, and I suppose the UC Medical Center; I'm more familiar with the Davies phenomenon. Davies and places like it became another social gathering place, in a weird sense. While you were up there on the floors visiting your friend or lover, you'd take a break; you'd go downstairs for coffee in the cafeteria, and there were all those other gay men and lesbians also taking a break. And you got to know some of the other people who were going through the same thing, which certainly helped for support, as well as just meeting other people. What a strange twist--the hospital cafeterias become a meeting point for gay people.

Comparing San Francisco General and Davies

Hughes: Do you have any comments to make about your impressions upon walking into San Francisco General, as opposed to Davies?

Helquist: Oh, yes, definitely. The times that I was at General, clearly it's a big institution; there's a lot going on, and when they had a lot of AIDS patients, and even establishing the clinics, it was a little overwhelming. It was busy; it was pretty well organized. It was before the point where they were swamped with

AIDS patients, but there was a lot of activity. It was not like you'd lost any of your human qualities or were treated that way, but it was just so much larger. It was more institutionalized.

Whereas Davies seemed much more manageable for patients. The floors were smaller. You'd get to know some of the staff over time. It was friendly. They were willing to let people put posters on the wall, bring flowers and balloons in, and let lovers stay late into the night with their partner/patients, which was kind of new at that time.

Hughes: Did you feel that the Davies group was as up on the latest regarding AIDS as the group at San Francisco General?

Helquist: I think so. The primary AIDS physicians in the city, who had most of the AIDS patients, were very close. It was a relatively small circle of physicians in those days. Steve Mehalko, who was Mark's physician, was a community doc. He had an office, actually, in the Davies Medical Office Building. He was very up-to-date on everything, even though he wasn't part of the UC-General complex.

I'm sure there were people who had physicians who were not very knowledgeable and from whom they probably didn't get very good care for that reason, and for whatever other reasons. Maybe they didn't have the choice to move on to someone else with a better knowledge of AIDS medicine. I'm sure the physicians would give you a perspective of being overwhelmed, and probably feeling resentful that there were so few of them who were handling AIDS patients, that they carried so much responsibility. It's not something that I think was noticed from the patient side so much: the physician was there for me.

Hughes: Did Mark choose to be at Davies, as opposed to the General?

Helquist: I think it was more a matter of, he chose to be with his physician, who practiced out of Davies. But Davies already had a pretty good reputation for sensitive AIDS care. I was just flashing on a number of experiences, walking in the hallways in Davies late at night.

One thing I was going to point out, maybe a profession-expanding factor for physicians and nurses, was also that they had these very articulate patients who when they weren't sick perhaps were doing their own research--I'm not saying they necessarily knew more than the doctors. In some cases, that was true on some points. But they were knowledgeable, plus they were going to speak up. There was some stuff they just wouldn't put up with.

I remember when I was visiting Mark when he was getting pretty ill, he decided he would like to have me stay there, first beyond visiting hours and then overnight, or kind of whenever I was ready to leave. We just did. So there was a little tussling for a while, but then some of the nursing staff was flexible enough to say, "Yes, this can happen."

Therapy

Hughes: What was actually done for him? He died in 1983?

Helquist: Yes, in June of 1983. He had KS; at first in his mouth, then on his skin, and finally in his lungs. He also had *Pneumocystis*. I don't remember much treatment for the KS. I know he had a really awful time on interferon. He really had very serious side effects, and it was very difficult. And then he had a number of mouth ulcers, which of course got very difficult too. There wasn't a lot of therapy available then.

Hughes: So it was mainly nursing care?

Helquist: Yes, it was mostly nursing care.

Hughes: Did he go off the interferon?

Helquist: Yes, he had to. It was just too hard on him.

Hughes: And it wasn't doing any good anyway, was it?

Helquist: No. Things were just moving so fast for him; he never really had periods of physical stability.

Hughes: You started to say something about walking down the halls late at night. Can you give me some of your impressions?

Helquist: Yes. One time, I remember visiting Mark in his room, and my being upset and going downstairs at Davies into the men's room, and there was some graffiti on the wall, something about "All faggots should die. They deserve AIDS." So I mean, the contrast was so stark.

And certainly the late-at-night walking the halls. I remember one of the early AIDS specials on TV, and it was on in Mark's room, and I didn't really feel like watching that. I just walked up and down the hallways, but it was on TV's in lots

of people's rooms. I felt deeply saddened by the enormity of what was happening to us.

Hughes: Was Mark watching it?

Helquist: I think he probably was. It was just that really odd feeling of having all this swirling around you. Sort of unreal that you're even there in the midst of it.

Hughes: Well, hospitals are unreal places to begin with.

Helquist: Yes, very much so.

His parents who lived in New York came out to visit several times, and there was initially a period of adjustment as his mother and I grew accustomed to each other.

Tensions between Friends and Parents

Helquist: One of the dynamics that was becoming more prominent is that a gay man's support circle, men and women, would organize themselves to do duty with him, cooking or staying with him or whatever. And lots of times, parents would come out who had been estranged from their son. It wasn't the case with the Feldmans, but they would come out and see basically this whole other family in operation, which they could either appreciate or resent, or want to establish their rights, hospital rights and otherwise. There was an undercurrent of recognizing that there two families present, and it was disrupting expectations for a number of people.

When I came into Mark's life, he'd been here in the city for ten years, and he had a very large circle of friends, and very close friends. I was the newcomer. Later, I realized that there had been some feeling of, "Why should he be the one to spend the time with Mark? Why should he be one of two nonmedical people to be with Mark when he died?" And I wasn't too aware of that; I wasn't really in a position to care about it at the time.

The Epidemic's Impact on Personal and Professional Lives

Hughes: Do you have any observations about why some people choose to become involved in the epidemic and some do not?

Helquist: Professionally?

Hughes: Yes, or in a social context.

Helquist: I am reminded that some of the early commentary about what was going on in the gay community here talked about what a maturing influence having to deal with AIDS was, and how people had to find their compassion. And that was true. But I remember thinking at the time, Well, wait a minute. I was a mature person before I got involved with this, and I was a caring person. It's not like I needed this crisis to all of a sudden develop these qualities.

But I think for some people, AIDS actually gave some definition to their lives. It did for those with AIDS, as well as those who found a way to contribute. There was a way for them to contribute and be connected in the community other than by being known socially, going to bars, or whatever. It was acknowledgment and recognition, as well as knowing that they were being part of helping out in the crisis.

So a lot of it was good will and opening our hearts. A lot of it was some notion of, Maybe this will protect me from AIDS, if I do good work for it. For some, it was a way to deal with their fear and panic, getting so involved with AIDS work and staying so involved that they didn't really have enough time to feel it personally. It helped them deny it.

And I think because AIDS hit this gay population, who already had a notion of, "We're kind of here on our own; we're already a defined group, a discriminated group, and society as a whole isn't necessarily going to come to our aid." We knew we had to do it, because maybe no one else would. And that's not so much the case now for others affected by AIDS, nongay people.

I would think that to capture the full story of the KS Clinic and UCSF and people who were involved, it would be important to emphasize how so many people took their experience and knowledge and were valued for it and became more international in their efforts. San Francisco provided a lot of people who shaped the response to AIDS worldwide.

Now that is a little pretentious for me to say that, but when things were just getting started, working with the CDC or with the World Health Organization, all of a sudden, a lot of people working here were becoming national speakers. And then they started being on the front line of some of the international work and the international conferences, and they were the front line for a long time.

Almost every facet of health care delivery on a global level began to be shaped, in part, by professionals who had their initial AIDS work experience in San Francisco. The local medical doctors and researchers certainly helped shape the medical response to AIDS. But so did the health care administrators. For example, Dr. Mervyn Silverman became the spokesperson for AmFAR with influence worldwide; Cliff Morrison, the nurse, shared his expertise with establishing AIDS care hospital units. Helen Scheitinger is now an international consultant and helped draft the curriculum for nursing aspects of AIDS care for the World Health Organization [WHO]. Jim Bunn of local TV KPIX became a public relations representative for WHO and developed the idea for the first World AIDS Day which has continued ever since. And the government's AIDSCOM project drew heavily upon those of us who had worked on AIDS in San Francisco, including Dr. Glen Margo, director of the city health department's Health Promotion Unit; Dr. John David Depree, active in East Bay AIDS work; myself, and many others from the AIDS organizations here who served as AIDSCOM consultants.

Public Recognition of the Scope of the Epidemic

Hughes: Is there a deciding event through which the scope of the epidemic begins to be appreciated?

Helquist: I was even trying to pinpoint a year, if not so much an event. Certainly, Rock Hudson's death in the larger world was a turning point. What was that, '85?

Hughes: Yes.

Helquist: So maybe even in 1984, the experience broadened with other organizations, other cities involved, being aware that this wasn't just a New York, San Francisco, and L.A. epidemic.

Hughes: And of course, the AIDS test underlined that.

Helquist: Yes. Very much.

Hughes: It's Hudson's death that really had an impact on the larger society, too. Was that the first event that captured the attention of the nongay community?

Helquist: It probably was, for the shock value of it. I think gay people approached it with mixed emotions: Good, we're glad this AIDS awareness is finally becoming larger. But also the same old thing: What's it take for the national public to become interested in AIDS?

Hughes: It takes a movie star.

Helquist: Yes, or it takes a Ryan White.

Discovery of the AIDS Virus

Hughes: Did the discovery of the virus mean much to you and to other nonscientists, nonmedical people?

Helquist: It didn't come as a surprise, because there was a lot of buildup that this is a sexually transmissible disease, probably also through the blood. Those connections were pretty clear.

I have a little story. I was tracking down the story about discovering the virus, and Don Abrams had given me a tip, sort of confidentially saying, "There's something that's going to be coming out of the federal government about this, and you might want to talk to this person." And to show you how things were different in those days, I just rang up Robert Gallo's phone, and he answered--[laughter] it's been a long time since he's done that probably--and he said, "I can't really tell you this for publication, but I'm going to go to London, and there's going to be a press conference,¹ and I'm going to announce this in New Scientist magazine." Which he did.

¹ On April 23, 1984, Secretary of Health and Human Services Margaret Heckler announced at a press conference that the AIDS virus had been discovered by Dr. Robert Gallo and named HTLV-III. (Subsequently, the isolation of HIV has been attributed to the team at the Pasteur Institute headed by Luc Montagnier.)

It was frustrating for me at that time when I was writing an article for the San Francisco Bay Guardian, a weekly paper.¹ Because of the timing of when they published, I think we were about a day after Gallo made his announcement.

Kaddish, October 1983 ##

Helquist: This is an anecdote showing how things have changed from the early days. This was in October 8, 1983, and I had become somewhat more prominent because of my writing about Mark Feldman and having contact with health care providers. Although there had been the first AIDS Candlelight March in May of 1983, in October a number of people who were interested decided to have another kind of recognition and exhortation among the gay population. This was an occasion when we closed off Castro Street and put a stage up, and there were a few speakers.

I guess because of some of my Jewish friends and through Mark, I became aware of the Jewish tradition of Kaddish, and we wanted to be able to remember people. What's the phrase--"We will not forget you." Obviously, we didn't want to read off people's last names. But I thought that it would make sense to get the first names of the men who had died, and to read them in front of the crowd, and to keep reciting the "we will not forget you" refrain.

Well, the only way to do that was to go to [San Francisco health department epidemiologist] Selma Dritz² and explain what we wanted to do and ask her if there was a way to get access to the names. She said yes. It wasn't like I was just anyone walking off the street, but there weren't professional links to the request. So she said, "Here, write down the first names, obviously not the last names." And she just pulled out a three-ring binder, and she had everyone's names written on it, and the dates of their death. She let me go through the binder and write down all the first names from July 1981 through September 1983. I did see some names in there of people I knew who I

¹ M. Helquist, "British Journal Set to Announce Isolation of Possible AIDS Virus," San Francisco Bay Guardian, 18-25 April 1984.

² See the oral history in this series with Selma Dritz, M.D.

didn't realize had died, so it was unsettling. Obviously, this kind of access to such names would be discouraged, if not outlawed, today.

Then at the event on Castro Street, a friend of mine and I were reading all those names back and forth, and repeating the line, which was pretty powerful. I think there were about 120 names of people who had died of AIDS in the city. But I always think of the occasion in respect to our justified concerns about confidentiality; not that Selma really broke that. Some people would say she shouldn't have done that, but it is a show of her trust of my intentions and a highlight of how things were more informal, that there was a more mutual effort to try to have an impact.

The Uniqueness of the Gay Community's Experience

Hughes: Well, Michael, is there anything else you want to say?

Helquist: Just a comment about the AIDS experience. I think it's very, very difficult for anyone who isn't gay or who isn't very close to the gay population to understand what gay people have gone through with AIDS. Just the notion of how many men--mostly men--could say, "I've lost three lovers, four roommates, ten friends--" just the numbers, for people in their thirties and forties. Maybe people in their seventies and eighties can relate to their friends' dying around them, but it is not beyond your expectation that that happens in your eighties. It's not like gay people have experienced something that you can't have; it's just, this experience is so personal and so pervasive, and our attention has been forced to be focused on it for twelve or thirteen years, that you realize that in some ways, outside of the gay population, you're kind of alone with that understanding and feeling.

I think of my family and my parents; they relate to me having AIDS, and are supportive and all, but they don't really have the sense of how many people I've lost or what that's been like. I've told them about some, but to tell them every week that there's someone else-- Well, you just don't do it. But it puts people close to the epidemic in a pretty unique position.

The positive side is that I think a number of people in their twenties and thirties have confronted death and dying, and what those experiences mean, and what they can do to you and do for you, that others aren't challenged to confront.

I remember when Mark was dying, he limited the number of people he would see, and he'd certainly stopped all of his organizational work and community work. One of the primary things I learned from him, he would say, "It all comes down to love." And that wasn't any new age feelings--this was just really basic. When a lot of the external things fall away by necessity, it just becomes more clear that love is really what it's all about and what matters.

There are a lot of people now who have gone through that experience. It doesn't shield them from the pain or the tragedy, but it's a broadening of their human experience which they--we--might not have had for ten, twenty years or more, or never. Lots of people don't ever get that, kind of being shaken so much, and have to then say, "Well, what's important here?" So gay/lesbian people who have been through this experience have a lot of accumulated wisdom, which is a tremendous resource for those willing to listen and learn.

Hughes: Thank you.

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THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984
VOLUME I

Jeannee Parker Martin, R.N., M.P.H.

THE AIDS HOME CARE PROGRAM OF VISITING NURSES & HOSPICE OF SAN FRANCISCO

An Interview Conducted by
Sally Smith Hughes, Ph.D.
in 1995



Jeannee Parker Martin, December 1996.

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INTERVIEW HISTORY--by Sally Smith Hughes

Jeannee Parker Martin was interviewed for the oral history series on AIDS nursing because of her administrative role in providing home nursing and hospice services in San Francisco to people with AIDS from 1984 to 1994. Her introduction to AIDS occurred at Yale New Haven Hospital where she was AIDS Program Coordinator in 1983-1984. In contrast to the San Francisco epidemic, intravenous drug users were primary targets of the disease, although gay men also were afflicted. Her oral account of this period includes comments on AIDS diagnosis, fear and stigma, and infection control precautions--themes which run through most of the interviews in the AIDS series with nurses and university and community physicians.

In 1984, Martin moved with her physician husband to San Francisco where she quickly found employment in the AIDS Home Care and Hospice Program of Visiting Nurses and Hospice of San Francisco, which had been providing services to people with AIDS since 1982. She tells from an administrator's perspective, rather than a care giver's, of the issues she faced and mastered--fundraising, staff hiring and training, program eligibility, staff support programs, and so on. Martin also provides a down-to-earth description of what services a visiting nurse might provide on a typical home visit to a person with AIDS. She also outlines the program's interactions with AIDS activities at San Francisco General Hospital, the San Francisco Health Department, and other city institutions central to the AIDS epidemic.

The Oral History Process

One interview was conducted in Martin's office in San Francisco at The Corridor Group, a business providing consulting services in health care, of which she is vice president. Personable and businesslike, she answered in forthright fashion and returned the edited transcript with a few comments and changes.

This oral history is of particular interest because it is the only one in the AIDS series which focuses in on the third "leg" in the San Francisco model of AIDS care, namely home and hospice nursing for people with AIDS. Because of this fact, it is an essential addition to the many series histories describing the other two "legs" of the model, outpatient and inpatient AIDS services at UCSF/Parnassus and San Francisco General Hospital.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA

Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

July 1998

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BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name JEANNEE PARKER MARTIN, RN, MPH

Date of birth 05/17/55 Birthplace Delaware, Ohio

Father's full name George Joseph Parker

Occupation Physician Birthplace Columbus, Ohio

Mother's full name Ruth Rosalie VanVactor Parker

Occupation Nurse Birthplace Shawnee, Missouri

Your spouse Michael J. Martin

Occupation Physician Birthplace Decatur, Illinois

Your children Maria, Christopher, Thomas
(10) (7 1/2) (4)

Where did you grow up? Delaware, Ohio

Present community San Francisco, CA

Education BS Georgetown University 1978
MPH York University 1981

Occupation(s) Nurse; Home Care Administrator; Health
Care Consultant; Clinical Faculty - UCSF Nursing School

Areas of expertise Home Care / Health Care

Other interests or activities Golfing - children - 3; running, swimming, skiing, reading, traveling, etc.

Organizations in which you are active CAHSA, IAH, NPH
Private and trade associations

INTERVIEW WITH JEANNEE PARKER MARTIN

I EDUCATION

[Date of Interview: January 26, 1996] ##¹

Hughes: Start back, would you please, with where you were born and educated, and your career up until the time you first became aware of the AIDS epidemic?

Martin: I was born in Delaware, Ohio [in 1955], which is a small town about twenty-five miles from Columbus, and was educated in the Catholic and public school system there. I then went to college at Georgetown University in Washington, D.C., where I initially was in the School of Languages and Linguistics, and then transferred to the School of Nursing and essentially double-majored in languages and nursing, although that's not an official designation at Georgetown. You can't double-major across two schools; only in one school. I graduated from the School of Nursing in 1978.

While I was at Georgetown, I was very interested in international programs, so I did some traveling and one study abroad semester at Universidad Catolica in Quito, Ecuador. Then after I graduated in 1978, I took a group of nursing students on a practicum semester to Guatemala. So I spent about a total of two years in Central and South America. The relevance of that has to do with my interest in different cultures, and how I ultimately got involved with AIDS work.

Then, after Georgetown, I worked as an Assistant Nursing Coordinator at Georgetown University Hospital from 1979 to 1981, prior to going to graduate school. I decided to get my master's in public health administration, because I felt it was the broadest base of information that I could get at that time. So I studied epidemiology and public health administration while I was at Yale University School of Epidemiology and Public Health, from where I graduated in 1983.

¹ ## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

II THE AIDS EPIDEMIC

AIDS Program Coordinator, Yale New Haven Hospital, 1983-1984

First Encounter with the Epidemic: A Book Project

Martin: My entrance into AIDS is purely coincidence, not probably as coincidental as for some other people. I needed a job in New Haven the year after I graduated, as my then-boyfriend, becoming fiancé, now husband [Michael J. Martin], was finishing up his residency. So I applied for a job at the hospital as an infection control coordinator. Because I had just finished my M.P.H., that was a somewhat likely transition at that moment, although I never had any aspirations to be an infection control coordinator. I was never in the mode of being just a staff person.

The person who interviewed me said, "We have this position we're creating for an AIDS program coordinator here at Yale New Haven Hospital, and we think you'd be a good person for it. Would you be interested?"

Hughes: Now, this is 1983?

Martin: Right. I had just finished graduate school. It was May or June of 1983.

Hughes: Had you heard of this disease?

Martin: Yes, and that's why I became probably the most qualified candidate. My husband, who was a resident, was very close friends with an immunologist, John Dwyer, who is Australian. He was on the faculty at the School of Medicine at Yale, and now is also involved in Project Inform here in San Francisco, many years later. John Dwyer and Mike, my husband, were very interested in this disease. John had seen patients that were coming down with

AIDS, and of course, it was all perplexing then and nobody quite knew what was going on.

So they decided to write a book. I typed the manuscript for this book, which never was actually published--as far as I know, it never went anywhere. Typed it as the nice fiancée. [laughter] So the only reason I knew anything about AIDS was because I typed this manuscript, and I typed it with great editorial interest, not academic interest because of the subject, but because Mike was writing it and I wanted to make sure it was well written. So I paid a lot of attention to what it said, and of course, I was in public health school, so it was interesting from an infectious disease standpoint and so on and so forth. So I didn't just take an interest as a clerical support person; I took a great interest as an epidemiologist.

Hughes: What was the thrust?

Martin: Gosh, if I recall, they were trying to tell people there was this new disease out there; the intention of the book was to inform. I haven't really talked much about this book, and I don't know whatever happened to the manuscript. Mike probably still has it. They were trying to inform the public that there was something going on out there, and this is what it looked like. It was written for the public, not for the academic world, if I recall correctly.

Now, Mike has written another book, not about AIDS, that was definitely for the public arena, that was published, so I may be confusing the intention of the two books now ten, fifteen years later. But it was very interesting at the time, and I think that they just probably moved on to other things. For my husband, this was just a passing, "Gee, this is an interesting topic; I'm a resident,"--John Dwyer was an immunologist on the faculty--"so let's do something together."

Hughes: Is your husband now an immunologist?

Martin: No, he's a businessman.

Hughes: Oh, I see. [laughter]

Martin: He's also a physician.

AIDS Program Coordinator

Martin: So when I went to apply for this job, which came up in the course of interviewing for another job, I actually was very familiar with what had gone on from '81 to '83, because they had done a lot of studies, and I may have read some of the articles for them; I don't really recall now. I knew a lot: I knew what had happened in San Francisco and Los Angeles. [tape interruption]

I interviewed for this position and took it because it sounded interesting, but more importantly, I needed a job to stay in New Haven for the year. My role was as the AIDS program coordinator for the hospital.

Hughes: Now, were you the first?

Martin: I was the first, yes. I reported to the director of nursing for medical/surgical services, but for all intents and purposes, I was working with this person, John Dwyer, in the Department of Immunology and with a physician who's an infection disease specialist by the name of Bill Green, who now is in New York. I have lost track of him.

Bill and John and I were, in a sense, a mini-team, because we had a great interest then in what was happening. I had a very interesting position as a nurse, and as a young woman--I was twenty-eight--in a heavily male-dominated medical environment. I had a lot of ability to coordinate their activities, because nobody really knew what was happening with AIDS. Everybody was interested and concerned, and probably there were subtleties of perplexity and fear. What did this really mean? Were they at risk? Nobody really knew quite yet. And I say that a little lightly and politely, but I think there were probably all these emotions mixed in.

So my role was to coordinate the services of any person with AIDS that came to the hospital, and also serve as more or less a clinical nurse specialist at the outpatient clinic. Yale New Haven Hospital was actually a very busy AIDS hospital. Gosh, I think there were hundreds of patients that we saw who were HIV-positive, although there wasn't the [HIV antibody] test in 1983-'84.

Diagnosing AIDS

Hughes: How did you diagnose AIDS?

Martin: It was purely based on clinical indicators: lymphadenopathy, *Pneumocystis*--purely clinical diagnoses, because there was no HIV antibody testing then. John Dwyer, the immunologist, did T-cell testing on everyone. In fact, those of us who worked with John were always the baseline. As all these tests are done, they find baseline norms, and the people that are the baseline are people around them--assuming we're all healthy, I guess.

I drew lots of blood while I was there, and did physical examinations on patients who were coming into the clinics, and worked with another immunologist and medical staff who were there. Immunology fellows, infectious disease fellows, myself, a psychiatric clinical nurse specialist, and a social worker, formed a team. There probably were others, but we were the core team.

Physician Meetings on AIDS

Martin: Key physicians at the hospital met on a regular basis to discuss what was going on with AIDS issues, and I facilitated all those meetings at which usually ten or fifteen physicians attended.

Hughes: Were those meetings held on a regular basis?

Martin: Yes, they were regular. I don't remember how frequently, but weekly or biweekly meetings.

Hughes: Just physicians, or were there patient presentations?

Martin: No, these were just physician meetings. These were looking at what was happening. Probably to a degree we did some rounding on patients, although that wasn't the purpose. I suppose we did talk periodically about the difficult patient or the patient that we were concerned about. And we were concerned about everybody, because it was a handful of patients at any given time that we're talking about, so everybody knew them. I still vividly remember the names of the people who were our first patients there. I can picture them; they're very much impressed on my brain.

Patients

Hughes: What demographic group did they come from?

Martin: Mainly IVDUs [intravenous drug users]. There were some gay and bisexual men. I would say that the heavy dominant group were IVDUs. What I am impressed with most this many years later is that there were IVDUs, but also, it seemed like there were a significant number of men who had other lifestyles: married men who also had this gay lifestyle in New York, and nobody knew in their family. And I have vivid memories of people about whom we had to keep everything confidential, even if their family asked us, who didn't know they had AIDS. I'm sure that still goes on to a degree in some locations, but that stands out in my mind.

But the IV drug users were the predominant group, and it was very mixed. There were men, women, and children who were impacted. The people who were gay or bisexual were less significant in my mind. They may not have been, but they are in my mind in terms of who we dealt with. Some people that stand out were also members of Alcoholics Anonymous and had buddies. They had pretty good, loose, informal support networks through AA, which was helpful in finding people, because we would expect them for clinic appointments, and they wouldn't come in, so we would call their buddies and see if they had heard from them. A lot of people were essentially homeless that we were working with. Maybe they would be in a hotel or an apartment for a while, but they were very transient.

Hughes: Were some of these people inpatients?

Martin: Yes. The clinic was one population, and then we had inpatients. There were probably eight to ten inpatients at any given moment.

Hughes: Scattered throughout the hospital?

Martin: Probably to a degree scattered, but most of them were on the medical floor. There was some concentration of patients, mainly because they had a medical illness, so that's where they were located.

I saw every single patient almost every single day. I would go in; I would visit with them. It was somewhat of an interesting role, which now would not exist to the degree that I had this role. I tracked their diseases; I did a little bit of infection control in terms of tracking what was going on with them; I visited with them, understanding where they were socially, making sure that their needs were being met, even though we had a social

worker. I also rounded with the immunologists or their [physician] attendings.

So I had an overall global picture of every single patient, and then people would ask me about them. I filled a role that today would not be accepted or tolerated because of budgetary constraints, but at that moment in time, I served kind of as a clinical nurse specialist and overall coordinator of these various patients. And I knew about all of them. If anyone asked me at any given time, I knew this, this, and this. I kept a very good notebook about them, which somebody from Yale asked to use for a dissertation. I kept a diary for that whole year, but I can't locate it. I know I never threw it out; it's in storage.

Hughes: What sort of things are in the diary?

Martin: I kept everything that I did every day. One of the roles that I played was providing counseling and guidance to community members who called in and had questions about AIDS. So we regularly got calls about people who had their T cells tested, and they wanted to know what this meant, and I was the confidential respondent.

Hughes: Did you take on that role because there was a need, or was that actually part of the job description?

Martin: Well, the role was undefined. I was the first person, so I think they said, "Let's see what this needs." I was energetic and interested and excited, and I have a tendency to be a little bit of a workaholic, so I was willing to do a lot of different things, and it didn't matter to me that it was or wasn't in a job description. I don't know if I had a job description. I probably had something, but I'm sure that it was a moving target, just because it was new. It was whatever the need was.

Hughes: You were obviously picking up on patients' social needs as well as medical. Is that a common approach in nursing?

Martin: Well, it's very common, and it's also very common in home care, because in home care, you've got to assess a very different environment. You're going to someone's home which may be this big: their bed is right here, and their dresser is here. Then you're out their door, because maybe they're living in a room of a garage. So you've got to assess quickly what the environment is, and what it can tolerate or not tolerate, and what the person's needs are in that environment.

Hughes: But you hadn't had that experience yet, had you?

Martin: Well, only to the degree that I had worked in Central America, and that was very much in community health. I had this great multicultural interest. AIDS patients certainly were a group perceived to be from a very different culture. So I think, initially, I was able to tie that in. Most people would say I'm very accepting. I hate to use the word tolerant, because I don't think that sounds accepting. It's sort of like saying, you live with it and it's okay. I think accepting is believing that other people have needs that are different.

Hughes: So you didn't have any trouble working with a stigmatized population.

Martin: None whatsoever. I suppose some people would say I was just very naive, but I don't think it was naivete as much as lack of knowledge. But I learned a lot, and as a part of this role, I got very involved in a group called AIDS Project New Haven, which was a group of gay and bisexual men in the community. There were a few other people, but mainly that was the group, although the people that we were seeing in the hospital were not always gay or bisexual men, and usually were not from that socioeconomic group.

New Haven is a very interesting community. There is Yale, but it's a very impoverished community, very drug-ridden. Not that they've made a lot of changes, but it's been a hotbed for the public health department there to do studies on the drug-using population, and on the maternal-child population. They've done lots of studies on teen pregnancies. It's a city where you'll be on one corner and it's a very low socioeconomic area, and the next corner is actually fairly affluent. I always found that very interesting, because I hadn't lived in an environment like that. In fact, I lived right next to the hospital, which I didn't know was the highest drug-dealing corner in the city. And when people who were from there learned where I was living, they said, "That isn't where you should be living." But it was a nice apartment building, so I stayed there for a while.

Fear and Homophobia

Martin: We tried to work with the local VNA [Visiting Nurses Association] a little. We tried to work a little with the local hospice provider, Hospice of Connecticut in Branford, which was very renowned in the nation for its pioneering work in hospice care, but yet was very resistant to providing services for AIDS patients.

Hughes: Why?

Martin: I think there was great fear, not just for AIDS but because it appeared that this was a gay and bisexual disease, and people didn't understand. They just didn't know what to do; they were afraid that if they were around people like this, they would become like this.

Hughes: Was it fear of infection?

Martin: I think there was a fear of the disease and infection. There was this other fear, though, that was homophobia, which persists. I think that's still a real problem today.

Hughes: What about you?

Martin: You know, it just was not an issue with me. I don't think I knew what homophobia was. It wasn't part of the way I thought about things. I'd been around all these people all my life, in my travels and in my work, that had different values and different ways of doing things, and this was just one more. So I don't think homophobia was ever an issue.

Infection Control

Hughes: What about fear of infection?

Martin: I don't think it was a real issue, because I was learning then what they believed to be the modes of transmission, that really haven't changed. I believed that it was important to take all the infection control precautions, and I was very cautious with everything. I was drawing blood. At first, we didn't wear gloves, and then they said we had to wear gloves. And that was a long time ago, before infection control processes related to AIDS were understood. Every time we went into a patient's room, we had a mask, gown, and gloves on.

Hughes: Really?

Martin: Absolutely, and that was absolutely a standard that we maintained. When people didn't, I was kind of a watchdog, so I would say, "Listen, I noticed you--." In retrospect, we know that all wasn't necessary, but then we didn't. There was a lot of caution. And amongst the team, we were all pretty much on the same wavelength. I think everyone pretty much said, "We've got to follow these

precautions. But also we want to deal with the disease socially as well as environmentally."

Hughes: Now, these infection control guidelines had been set up by the hospital?

Martin: These were just standard infection control guidelines. Somebody had an infectious disease: you wore gloves; you wore a mask; you wore a gown.

Hughes: So the guidelines weren't particularly AIDS-related?

Martin: Oh, they weren't at all. Everyone was on total isolation, or whatever it was called then, where they weren't allowed to leave their room without a mask and a gown on, and we weren't allowed to enter their room without a mask and a gown on. So it was just like those pictures that you see in infection control videos, where somebody comes in and they're garbed. That's what we looked like. But it was important then.

Hughes: Was that upsetting to patients?

Martin: At that point in time, I'm not sure that it was so upsetting to patients, because everyone was a little uncertain about what was going on. I think depending on where you are in the country, today even, there's a different level of awareness.

Hughes: Even amongst the so-called stigmatized population?

Martin: I think so. That's my Midwest upbringing, but I think there's a lot of tolerance for, "This is the way it's got to be, so what's the big deal here?" There's still a lot of tolerance for that in certain populations. If they're offended by it, they don't say anything, which isn't necessarily good, but if they're offended, they take it as part of, "This is the way it should be."

For example, if I was in the hospital and somebody said, "You have to wear a mask, gown, and gloves, because we don't really know how this [disease] is going to spread," even if I was offended by it, I probably would say, "I understand, and that's okay." And not make waves about it. That's probably a lot of how it was then, that many years ago. I think the social workers had more difficulty, and probably understood the social, psychological dynamics more, because they would in fact go in to patients' rooms without mask, gown, and gloves on.

Hughes: Did you reprimand them?

Martin: Yes. We had to. It was my role to say, "This isn't appropriate at this point; we don't really know about transmission of this disease." I don't remember there being issues.

Hughes: In San Francisco, many of the care givers were gay. I assume that wasn't as true of New Haven.

Martin: That might have been true. I can't recall frequently seeing gay couples come in to the clinic, for example. And on the clinic staff, there was nobody that I recall that was gay themselves. They may have been--I don't recall.

Hughes: They weren't making it obvious, if that were the case.

Martin: Oh, no. I'm sure at that point they weren't.

I created a role for AIDS Program Coordinator, and then I left. The person who followed me was not the right person, and then the person who came next was in the role for quite a long time. Then I think things began evolving in terms of needs at the hospital and how things were handled.

Hughes: Were you communicating with the CDC?

Martin: Well, to the degree that we filled out reporting forms to identify people with AIDS.

Hughes: The CDC wasn't an occasional presence in the hospital?

Martin: Not that I recall. "60 Minutes" was. [laughter]

Hughes: What was "60 Minutes" interested in?

Martin: They interviewed the immunologist for a program on AIDS. It was "20-20" or "60 Minutes."

Public Speaking

Hughes: Which indicates that your program had some visibility.

Martin: I think it probably had quite a bit of visibility, primarily because it had some pretty high-profile people who were interested and participated in outside activities. For example, I spoke all the time that year.

Hughes: To what kind of groups?

Martin: Well, local groups, from home care to hospice providers to local businesses to going down to NIH for a meeting. I had never done anything like this before.

Hughes: What was your basic message?

Martin: We were educating about AIDS, just basic, "This is what AIDS is; this is how it's transmitted." It was a basic AIDS 101 course. The reality is that we didn't know a lot more than the audience; we just knew a little bit more, and we had some hands-on experience. But gosh, I spoke a lot. Then there was another person in the state, Bill Sabella--and Bill died about two years ago. He was in my class at the School of Epidemiology and Public Health.

##

Martin: His partner, Al Novick, who's at Yale, did a lot of very forthright sex education for people in the community, and was very controversial at the time, and probably still is. He's a controversial type of a person in his mannerisms and his mode of operation, I would say. Al taught me a lot about AIDS and how this disease was transmitted amongst gay and bisexual men. I mean, I didn't know. It just was not in my lexicon, and he really taught me and a lot of other people to understand. This was about a population that we didn't really know that much about.

Hughes: Does New Haven have an organized gay community?

Martin: Well, at that point in time there was a somewhat organized community, because they formed AIDS Project New Haven. But today, I would assume it's probably like many communities, where there's an openly gay population. It's an academic community, and more tolerant probably, accepting.

III VISITING NURSES AND HOSPICE OF SAN FRANCISCO, 1984-1994

Job Search and Hiring

Martin: And then I left my job there and moved out to San Francisco.

Hughes: Why San Francisco?

Martin: My husband got a fellowship at UCSF [University of California, San Francisco]. He was a Mellon fellow in epidemiology. As a part of that program, he got his M.P.H. [master's degree in public health] at [UC] Berkeley, and then while he was getting his M.P.H., he got his M.B.A. [master's degree in business administration] at Berkeley. The Mellon Fellowship was a joint program between UCSF and Berkeley.

When we moved out, I wasn't really sure what I was going to do. I had contacts at the Institute of Health Policy.

Hughes: So it wasn't necessarily going to be nursing?

Martin: Well, no, I had my master's in public health, and I was open to suggestions. I made a lot of contacts with people that people from Yale had told me to get in touch with. I was looking in the newspaper for a job. I didn't know if I wanted to stay in AIDS work. Is this really what I wanted to focus my career on? It had just been a job for me, albeit an interesting one. Although I was very connected to the people and very interested, and we all had a very good rapport, it still was just a job.

When I came out here, I applied for a variety of jobs, all of which I was offered. But the most interesting one was as the AIDS Home Care and Hospice Program coordinator at Hospice of San Francisco.

Hughes: Now, why did you think it was interesting?

Martin: Well, I'll tell you. I went to the interview, and I was pretty East Coast in my demeanor, with my proper suit and my little briefcase. Not that I still don't dress that way--this is Friday, and we're a little more casual on Friday [Martin was dressed in slacks]. It was a team interview, and everyone was very, very friendly. There was a dog in the interview, and it seemed like a fun job. It seemed like it would be very interesting, and it was something I had just done, so I was sort of familiar with AIDS. By far, I was the only person that they had interviewed that seemed to have this much knowledge for this position and any academic credentials. That was probably part of the reason they hired me. So I got the job.

Director, AIDS Home Care and Hospice Program, 1984-1991

Martin: So I took this job as AIDS program coordinator, and that was the first AIDS program coordinator that Hospice of San Francisco had had, and the first AIDS program coordinator for a hospice program in the country. The executive director [Hadley Hall] of the corporation, which was VNA [Visiting Nurses Association], Inc., was a very active member of the national and local home-care community, and had been very involved politically in getting legislation through and getting activities going. So he was instrumental. JoAnne Handy hired me for that job, and we've been close colleagues ever since.

She reported to Hadley Hall, who was instrumental in getting me involved in the community. Not that it wasn't part of my demeanor anyway. But I never would have had reason to do that if somebody hadn't encouraged me, I suppose. So he got me involved in local politics, meaning the public health department politics, not city. Well, to a degree it was city politics. I mean, I was meeting with everybody within a month of the time I was there, because this position and the program were publicly funded. It was a grant through the City and County of San Francisco.

Soon after that, I was speaking at national home-care conferences, because Hadley had said, "This person has got to speak at these conferences." And I loved doing that stuff, so it was just right up my alley. So of course, I took the ball and ran with it.

We had a program to provide services to people with AIDS in their homes, and it was an interdisciplinary team approach to care. We modeled the approach after the hospice program, which is an interdisciplinary team approach to care. We had a lot of AIDS

patients, but it was still a very small program, not much funding. We went back to the city and we said, "The only way this is going to work is if we get more funding. We should model it after the hospice program, and we'll get funding whenever we can from Medicare and Medi-Cal and private insurers."

We got the funding, and that funding continues today. There is enormous funding support from the city to what is now Visiting Nurses and Hospice of San Francisco. So we developed a team approach, and that team then served the needs of people with AIDS in their homes. We provided nursing, social work, home health aides, a physical therapist or rehab[ilitation] therapist whenever necessary, volunteers, spiritual care counselors and bereavement counselors.

The key element to that program, and the key element, I think, to why the San Francisco model works is because of the attendant care program that we established at VNH [Visiting Nurses and Hospice] that started in 1984 to complement the hospice services. Without that attendant care program, without the support that we provided to patients at home, patients would never have left the hospital. Nobody else was serving these patients at home. They were staying in the hospital for weeks and weeks. It was common then. And when this program started, we started shifting people out of the hospital and working with them at home, allowing them to remain at home. We administered medications or helped them understand the medications, helped them with transportation to and from doctors' appointments, et cetera. So it was really a very important program.

The key element of that program was the attendant care program, because patients had lovers; they had family members; they had all kinds of people who were working during the day who weren't available to stay with them, and the patients were frail; they were often demented, and needed somebody with them.

So we were able to get a whole group of people out of the hospital and sometimes prevent them from ever going to the hospital, so that they could get their care at home. I think strongly that the program kept people out of the hospital and kept the costs of care lower. I don't know if you're looking at articles on cost-of-care issues. There aren't good ones, and there aren't a lot, but the ones that are out there clearly document that this out-of-hospital care was important to keeping the costs of care down.

And I think we can talk about the San Francisco model. There's the prevention side, and the education side that the San Francisco AIDS Foundation provides, and there's the volunteer

support that Shanti Project continues to provide, and then there's the AIDS Health Project that provides mental health services to people with AIDS, and so on and so forth. But without this home-care program, none of those other programs would have worked.

It was Hadley Hall's leadership that got it going. It's great for me to take a lot of credit for it, but Hadley was the one who went to the city in the first place and said, "Listen, we can't do this without some funding." He knew [Assemblyman] Art Agnos and said, "Listen, Art, we need to have some money for this program." He went to [director of the Department of Public Health] Merv Silverman at the time and said, "We need some money for this program." And they gave us the money for that program. If it hadn't been for Hadley's pushing them, the program wouldn't have started.

The program actually started before I arrived, and it was only attendant care. It was a subcontract that the then Hospice of San Francisco had through the Shanti Project. Somehow, the funding was related to Shanti, and it started in the spring of 1984. I came on board in August. They had expended all of their resources by mid-August. They were providing twenty-four-hour-a-day care to anybody that needed it, so they had spent all their resources. When I came, I didn't know that they had spent everything, so there was actually almost no money immediately after I arrived.

So, of course, I was the person charged with figuring out how we were going to keep the program going. So from there, we got more money, we created a better system of accounting for services we were providing, and were able to keep thousands of people out of the hospital.

Executive Director, Hospice Programs, 1986-1991

Integrating the Hospice and AIDS Home Care Programs

Martin: That program continued to grow, and in late 1985, the Hospice of San Francisco traditional Medicare program closed because of a Medicare dispute, so the only thing that existed there was the AIDS program. And shortly thereafter, we restarted the hospice program. It was a matter of shifting things around and working this dispute out with Medicare. In 1986, we merged with what is now California Pacific Medical Center. In early 1987, the Medicare program restarted. The AIDS program always was there, but I was placed in charge of all the hospice programs.

So at that point in time, we collectively started looking at how we should integrate the teams of Hospice and the AIDS Home Care programs. We thought such integration would help prevent burnout that was occurring in staff, and would potentially help to attract more staff to work in the programs. There would be less problem with burnout and difficulty with staff caring for a very challenging population; the patients were physically, mentally, socially, and financially impaired. They just needed so much, and continue to need so much. There are different resources now, or we understand better how to use those resources, perhaps.

So we actually integrated the AIDS Home Care and Hospice teams with the traditional hospice program. Over time, we reestablished these programs, so that there was a separate AIDS Home Care Program and a separate Hospice Program. It's a technicality in administering the program, but I think we've really been able to look at the AIDS Home Care and see what worked and what didn't work, and have been able to provide insight for the nation into how to provide services to people with AIDS at home. I probably have done more than 300 or 400 presentations on AIDS over the course of a ten-year period. I haven't done so many in the last couple of years, but prior to probably two or three years ago, I was speaking as much as two to three times a month.

Hughes: On the home care aspects?

Martin: Yes. Sometimes it was four or five presentations in a couple of days. So I did a lot of speaking.

The program itself was important because of our attendant care program and the staff nurses who were real specialists in AIDS care. Without the attendant care program, though, I believe it wouldn't have worked. We would have just been another home-care program relying on Medi-Cal and Medicare and not been able to provide as much service.

Obtaining Additional Funding

- Hughes: I have a letter and proposal here from Hadley Hall that's written to Volberding in response to a letter from Volberding.¹ Why did Hadley become aware that there was a problem?
- Martin: Well, I actually know why. In 1981, Hospice started seeing AIDS patients. We started getting referrals into the Hospice of San Francisco programs, and they became more and more challenged to provide services to people with AIDS, because they required so much support. There was no funding from Medi-Cal and Medicare to provide the required support to keep patients out of the hospital.
- Hughes: That is a problem Hadley addresses. [tape interruption; Martin reads documents]
- Martin: There was already funding for attendant care at VNA through the Shanti project at the time this letter was written, and additional funding was received for a five month project. This \$384,000 was the basis of the project when I came on board, August 15, 1984. Maybe it was funded in July, but I came on board in August. It ended in November. We had run out of money by the time the end of the program had arrived. And that's when we started getting this other funding, \$311,000.
- Hughes: That letter raises the question of which way the problem originated. It could be that people such as Volberding at San Francisco General prompted the community response, or it could have been apparent in the community, namely, to Hadley Hall. This letter obviously responds to correspondence which I've never seen from Volberding.
- Martin: Right.
- Hughes: Was this need first perceived by Hadley Hall, or was he prompted by the concern of the staff at San Francisco General, which had to find some way of caring for patients when they were discharged?
- Martin: I think it's probably hard to know which was first, the chicken or the egg, because the hospital was discharging patients, and the VNA was seeing patients that were discharged. The complexities of

¹ Hadley Hall to Paul Volberding, June 4, 1984, and attachment: VNA of San Francisco. Proposal to the City of San Francisco for the Establishment of an AIDS Home Care and Hospice Unit [n.d.]. (AIDS History Project Archives, Special Collections, UCSF Library, Ward 86 papers, carton 1, folder: letters to PV, A-J 1984.)

care were great, so VNA was saying, "We can't do this unless we have more money," which caused a problem at San Francisco General. The change in policy was that they were not going to accept patients who didn't have full coverage unless they got more money. And that prompted this grant application: "You give us a project amount, and we'll care for the patients within the project budget, but we don't want this to be a fee-for-service project." And that project-based program is what worked for many, many years. I think now they've reverted to a fee-for-service project.

Hughes: Really? Because one of the points that was made in the grant application was that the fee-for-service method of payment produced a lot of problems--cash flow problems, training problems, etc.

Martin: Yes. And it's contrary to what is being done now on capitated arrangements. What people are doing in capitated arrangements is saying, "Here's your lump sum of money for this population and you take care of them, whatever their requirements are; it's your problem, not ours." Fee-for-service says, "Your incentive is to make as many units of service as possible, because we're going to pay you by the unit of service," which in home care is a visit. So the fee-for-service system has less incentive to be cost effective, even though there are controls over it in managed care.

Differentiating and Amalgamating Home-based Programs

Hughes: How do you differentiate the activities of the three organizations that are involved in AIDS community care: the VNA, Home Health Services of San Francisco, and Hospice?

Martin: You're taking information from the 1984 letter, which didn't exist after that. Well, there's history around VNA of San Francisco and its mergers. In 1981, the San Francisco Home Health Service merged with Hospice of San Francisco, and in 1983, those services together merged with VNA of San Francisco.

The parent corporation became known as VNA, Inc. VNA of San Francisco provided traditional intermittent health services, which means people whom we expect to get better are going to get services. Hospice of San Francisco provided care to people who were terminally ill, and San Francisco Home Health Services provided adult day health care services. So they didn't provide home health services after 1984. In 1983, they provided adult day health and social services to seniors. It was a senior program.

The problem that is expressed in this is that, in 1983, the city was working with VNA of San Francisco and Hospice of San Francisco. Even though it was one corporation, it was two different subsidiaries, and that was confusing. Hadley raises in this letter that that was confusing, so you give us a lump sum, and you'll only have to deal with the AIDS Home Care and Hospice Program, which is what is proposed in here. He says, [reading proposal] "To solve some of these problems, it has been proposed that an AIDS Home Care Unit be established within VNA of San Francisco. This unit will be responsible for providing both home care and hospice care for patients with AIDS. The City has been asked to finance the cost of the actual team of nurses, social workers, home health aides, attendants and others who are needed to carry out the work of this unit."¹

AIDS patients then went to this program, once this funding was granted--well, initially, it wasn't quite that clear-cut. But after a certain point in time, all the AIDS patients went to the AIDS Home Care and Hospice Program.

Hughes: Why wasn't it clear-cut immediately?

Martin: Well, in 1984, when the funding first came in, the funding only supported care for terminally ill patients, so the intermittent patients were still cared for in what was then called VNA of San Francisco. So VNA cared for some, and Hospice cared for others--the same corporation or same parent, with two subsidiaries. They were in different buildings.

Hughes: What was the incentive to combine all patients in one program?

Martin: Well, two separate programs were inefficient and less effective. One group of patients was being seen by staff who really didn't have any expertise nor desire any expertise in this disease, and felt this wasn't what they wanted to be doing. We had this pot of money in our program, so we felt if we combined the programs, it would be better for the patients and possibly better for some staff.

Because Hospice of San Francisco and the AIDS Home Care Program got all this extra funding and a lot of attention, they were seen as an elitist program, and there was a lot of tension between the intermittent program and the hospice program. In 1986, we moved into the same building and began to break down some of those barriers. We all moved into 401 Duboce, which is where Maitri AIDS Hospice is now, at Church and Duboce, and then things

¹ Ibid.

started to change pretty dramatically. By that time, we had already created the AIDS Homecare and Hospice Program, so every referral for AIDS services came to the same unit, essentially came to the same intake person, et cetera. And then when we moved to the same building, it was even easier, because tensions were less, since we could be face-to-face and everybody saw each other.

So there wasn't confusion after a while. But in the beginning, it wasn't so clear-cut, because there still was a hospice program that got all the funding, and an intermittent program that didn't get any funding. And unless AIDS patients came to Hospice, they weren't going to have access to the extra funding, because it was designated money.

Hiring and Training Staff

Hughes: Did you have to hire new people and train them? Taking care of AIDS patients requires special skills.

Martin: We did hire all the staff, starting August 15 of 1984. I came on board and a home health aide, Beatrice Autrey, came on board at the exact same time. And after that, I hired all the staff for the AIDS Home Care and Hospice team.

Hughes: What were you looking for?

Martin: Well, typically we were looking for people who had experience in dealing with terminally ill patients, cancer-oncology-pain-management-symptom management expertise.

Hughes: Could you find such people in enough numbers?

Martin: Oh, yes, we had excellent staff. In fact, we really had terrific staff. At that time it was a very small team, so everybody knew each other very well. It was like those first AIDS patients: you have vivid recollections when the numbers are smaller. The team was excellent; we had excellent nurse clinicians, social workers, and home health aides. The rehab therapists weren't really part of the AIDS team; we purchased that service from the VNA component, from the intermittent side.

The volunteers were very dedicated to caring for people with AIDS, many of them from the gay population here in San Francisco.

Hughes: How were volunteers recruited?

Martin: Well, probably in a variety of ways. By word of mouth, and we also distributed some fliers, advertising for volunteers. Periodically, we had an article in the paper or an advertisement in the BAR, the Bay Area Reporter. We may have even had an ad campaign for volunteers at one point in the BAR.

Hughes: Was there a training program?

Martin: Yes. Every three months, we conducted a volunteer training. And then whenever we had a new staff member, we did an AIDS- and hospice-specific orientation for them. Over time, we developed a videotape that was specific to the home care of people with AIDS, the AIDS Home Care and Hospice Video. We also developed a manual, the AIDS Home Care and Hospice Manual, which was published in '87 and again in '90.¹ The video and manuals were really meant to educate not just our staff. These products were funded by a grant that was intended to disseminate information about AIDS. It was a Robert Wood Johnson grant that initially supported it. That helped disseminate information around the country.

Home-Care Visits

Hughes: What sorts of things would happen on a typical visit to a patient with AIDS?

Martin: Well, today, a typical patient is a person who is getting infusion therapy at home and who, as always with AIDS, has multiple infections at the same time. It's hard to describe a typical day. But a nurse would visit that patient, do a complete physical assessment on the patient, determine what kind of treatment planning they need for their care to remain at home. So if they are getting infusion therapy, which is ordered by the physician, then the nurse would have to plan how frequently nursing visits will have to be made to maintain the person at home, how often the infusion and pharmacy will have to be delivered to the home, and how that will be delivered.

The patient, because he's frail, might have a decupitus ulcer, and the nurse might be dealing with nutrition as well as wound care issues related to the decupitus ulcer. She might be dealing with respiratory illnesses, so maybe doing some pulmonary

¹ J.P. Martin, A.M. Hughes, and P. Franks. The AIDS Home Care and Hospice Manual. San Francisco: Visiting Nurses Association, 1987 and 1990.

care for that patient. Then she's also coordinating the care that the other staff are providing for that patient.

Because I'm not a practicing clinician, I'm not going to give you the same sense of what they do as an active care nurse would. I'm really an administrator. The nurse then would coordinate with the physician to make sure the orders and the treatment plans are in place, and also coordinate with the other team. Most patients would have a home care aide coming in. The home care aide provides personal care assistance to that patient, and would come in as much as four or five times a week, depending on the needs of the patient.

Hughes: To do housekeeping?

Martin: No, to do personal things, like bathing, making the bed, maybe doing range of motion if the patient is debilitated and needs some assistance with strengthening exercises, and might do some light housekeeping. They're not housekeepers. They might prepare meals, and they might even run errands if it's related to the illness.

Then there are volunteers that might come in and sit with the patient, provide the family or a loved one with some respite. Rehab therapists might come in if the patient has a need for strengthening exercises, or might be losing their vision and might have a need for reevaluating their home environment, so that they have the right items to facilitate them staying at home, feeding themselves, caring for themselves.

Hughes: Who makes the decisions about who comes and when?

Martin: Typically, the nurse case manager will make the decision up front initially, and then a rehab therapist or a social worker will make determinations as to what's needed by these disciplines. That's the ideal situation. The payer also makes determinations.

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Martin: Often what the patient really needs is custodial care, and the insurer may not allow for custodial care, because custodial care is really personal care assistance and supervision, and insurers don't want to pay for that, even though over time, it might prevent the patient from being in the hospital. Great inroads have been made, and because of capitated arrangements, the provider may help to make some of those decisions now, putting in lower-cost care versus a nurse.

The other thing for many patients who have ongoing needs is the residential care system in San Francisco. There's Coming Home Hospice, that opened in 1987, which is an unbelievable residential care program that's part of VNH.

Hughes: Why unbelievable?

Martin: It has staff that meets the needs of people with twenty-four-hour care needs. It's a facility with a great setting that combines a residential feel with an institutional environment, so patients are allowed to still remain out of the hospital and get group-related care, because they're in a residence. It's not as costly. So they might be prevented from going to some other environment, or being at home in a very unsafe environment.

Hughes: Now, did the disease push developments in certain directions that were new to home care?

Martin: The disease is multifaceted. In other chronic illnesses, with the elderly, there are usually multiple problems. The patient may have cardiac disease, diabetes, and a hip replacement. They also may have limited finances. They also may not have the support structure to help support them at home.

I think the difference with AIDS is the acuteness of all the problems at the same time. A patient might have three or four or five or six diseases that are really acute at the same time, and over a very brief period of time. Somebody who has cardiac disease and somebody who has diabetes have had those chronic illnesses for years. They have maybe not adjusted to those illnesses, nor may have their families, but they've had them for many years.

Now we have some people who have been diagnosed with AIDS for ten years, but not very many. You're usually talking about a two- or three-year period where all their systems just start to fail. And they're young. And they're not at a point in their life where they're thinking of all these things happening to them. So I think the difference is the severity and the amount of diseases occurring at once. Therefore, in home care what's impacted is the amount of service that's needed, which is different in that regard, although not new. You could say the same thing about a chronically ill elderly patient who has many, many needs. I think what pushed the buttons was the severity and the complexity and all these things going on at the same time. So not only does a patient have *Pneumocystis*, but also he's losing his vision, and he has neuropathy so he has difficulty walking.

You can compare AIDS to Alzheimer's disease, where multiple systems start to go, and they become demented. That is very, very difficult for family members, who see subtle changes, and then suddenly the person is very debilitated. It may occur over twenty or thirty years. In AIDS, it occurs over just a few months or over two or three years, and I think that's the difference.

Eligibility

Hughes: What were the criteria for eligibility for the AIDS Home Care and Hospice Program?

Martin: The person had to be diagnosed with AIDS and to have a need for skilled nursing services, which is a technical definition.

Hughes: That was it?

Martin: Those are probably the primary ones. In the hospice program, there are more requirements. You have to have a disease prognosis of six months or less.

Hughes: Was there ever a problem in defining who exactly had AIDS?

Martin: That's not really so much a problem in home care, because home care is not defined necessarily by the definition of AIDS. It's defined by the needs of patients and their requirements for skilled nursing care or rehabilitation services. So in social service programs, the definition of AIDS is more of an issue. In a home care program, the person would still be eligible for services if they met a certain set of criteria defined by their insurance provider based on skilled care needs. If they have AIDS, they would be eligible for certain insurance coverage, and also may be eligible for some additional funding. That now has to do with Ryan White Care funding and City and County of San Francisco funding.

Fear

Hughes: Was there a problem with fear amongst the care givers?

Martin: I don't think it was ever a major problem here in San Francisco. The biggest problem was the intensity of the disease; it really caused a lot of stress in the staff.

On the other hand, in the staff that existed within VNH, there probably were some staff who made clear decisions that they didn't want to take care of AIDS patients. And it probably wasn't ever an issue, because we had a separate AIDS team, so if they didn't want to, it went unnoticed.

Hughes: They didn't have to.

Martin: It was never an issue. I wouldn't say that they wouldn't have had to if push came to shove, but they didn't have to since we had a dedicated staff.

Staff Support

Hughes: Was there a staff support system?

Martin: Well, we did a number of different things. We had a support group for every team, so there were as many as three support groups at one point in time for the staff who were providing services. Some of the support staff in the office were eligible to go if they wanted to, but typically, it was field staff members who used these groups for support. The volunteers also had support groups facilitated by an outside individual, somebody who was anonymous, supposedly, to the organization.

The other thing we did, and then we rescinded it--it took a very long time to rescind it--was we implemented a ten-hour-day structure so staff would work four ten-hour days and have one day off--essentially three days off a week. Not in a row, but three days off. That was a good system to give staff more of a break, but it's a terrible administrative problem, because all the time you're trying to cover somebody's caseload. So we tried to rescind that, and there was a great outcry amongst the staff, which one would expect. The staff eventually was allowed to continue working ten-hour days.

Teams

Hughes: How many teams were there?

Martin: It's a little confusing, because our teams were mixed. We had three teams, and those teams were mixed with hospice non-AIDS and AIDS patients. And then we segregated those out, so there was one

AIDS home care team for intermittent patients. And then the hospice-appropriate patients were intermingled with the other hospice patients on the AIDS home care team. There were additional patients in the hospice program. So there was one team that was AIDS only, and then the hospice AIDS patients were intermingled with other hospice patients. I think this approach continues today.

Hughes: Did those teams stay fairly constant? I mean, was it the same group of people working together most of the time?

Martin: Yes. I'm not talking about a mini-team of two or three people; I'm talking about a team that's a unit: thirty to forty people who formed a team that covered the same geographic area. And that team cross-covered for each other. It was an interdisciplinary team of nurses, social workers, and home health aides; sub-teams would see the same patients. So there were sub-teams within a bigger, interdisciplinary team.

Hughes: A sub-team worked together.

Martin: Yes.

Hughes: And they knew each other.

Martin: Well, the bigger team also knew each other. It's just that there were only a few social workers, and there were a lot of nurses, so the social workers worked with a lot more nurses.

Interactions with Family Members

Hughes: How much interaction was there with family and loved ones?

Martin: All the time. I'd say that one of the biggest problems in terms of time management for the staff was the interactions they would have with family members. They had social concerns and psychological needs that needed to be addressed, so the staff had to deal with them. As I said earlier, at times, there's an acceptance of, "This is how it has to be." If you deal with an elderly couple that's expecting cardiac disease, for example, to be a part of their life at this time, and now they're deteriorating, there is a level of acceptance.

Whereas in this disease, AIDS, a family may not have known their son was gay, may have come from Ohio and maybe not known he had AIDS, and been dealing with this news for the first time. Or

his lover, who may also have AIDS, is dealing with issues himself. So there are complicated psychological and social issues associated with AIDS that are different than dealing with the typical chronically ill patient.

If you deal with chronically ill patients, there are subtleties of age, preparation for the disease, and knowledge that you've been sick that help prepare yourself and others. And, if your grandfather has end-stage cardiac disease, that's something he'll probably tell you: it's not usually something he will hide because he's afraid of your reaction or embarrassed.

Whereas your son may have been talking to you for a year, and you didn't know he was really sick. The partner may also be dealing with very critical issues: the family is now coming, or the family won't talk to them, and complications of who gets ownership of this person's [the AIDS patient's] property. So there are different dynamics in AIDS.

Associations with San Francisco General

Hughes: What was the program's connections with the AIDS group at San Francisco General?

Martin: Very closely connected. I still remember the first day I ever walked into a Ward 5B meeting. Since the program started, there has been a very close linkage to San Francisco General inpatient and outpatient services, primarily because this program was able to fill a need that they had for home-based services, and we wanted to fill that need. So we developed a very close working relationship. In 1984, there was a small core group which was leading the way, I guess you could say. There was Alison Moed at San Francisco General, and there was Tim Wolfred at San Francisco AIDS Foundation, and there was Jim Geary at the Shanti Project, and Jim Dilley at the AIDS Health Project. We, at AIDS Home Care and Hospice Program, established a very close working relationship with all these groups, but particularly San Francisco General Hospital inpatient wards and ambulatory clinics.

Ward 86 after a while became the central focus of AIDS services there, because most patients came in and out of Ward 86 instead of the inpatient unit. So the working relationship continued to be very close with them. There have been challenges certainly, with different staffing and as the disease has changed. But I would say always the relationship has been strong, even if

it's been challenged at different times. Challenges really have to do with control of patient needs. Who's the real decision-maker was the challenge that came up.

Hughes: So it wasn't a given that it was going to be the physician making the decisions?

Martin: Well, technically, yes, but practically, it was the case manager. There is a case manager over at San Francisco General, and then there'd be a case manager for home care. And who knew the most about the patient? It was a toss-up. I don't know. But that's where some of the pulls and pushes come, when you've got case managers who all know a lot about the patients, and they all know the right directions to go in. It's which is the right direction for that moment that becomes the challenge. Those roles as case managers were not easy to define, not that they weren't clearly defined. They just weren't easy, because one person is dealing in the home setting, and one is dealing with the patient at a clinical point in time, which is two different interactions.

Hughes: Did AIDS prompt greater problems or different problems?

Martin: Well, there's a whole different level of advocacy around AIDS than there is around some other illnesses. VNH (formerly VNA of San Francisco) serves probably 1,200 patients at any given point in time, and of those 1,200 patients, several hundred of them are AIDS patients. In the San Francisco community, there's a huge level of advocacy around services for people with AIDS that doesn't exist for people who have end-stage cardiac disease, who are debilitated, who don't have a spouse, who don't make any money any more; they're living off of limited Social Security incomes. There's just a whole different level of advocacy, and it's because it's a young group of people being affected and cared for by a young group of people who are interested.

There's a different level of advocacy when you see your partner sicken and die, or your staff person who's your age sicken and die, than there is if it's an older person. It's the same thing that happens with children who are sick: there's a lot more sympathy poured out to a child who dies of a childhood disease, versus an elderly person who dies from an elderly, chronic disease, even though each is equally important.

Hughes: How was your program related to the Department of Public Health?

Martin: The most important department at the public health department for us as an organization was, and probably continues to be, the AIDS Office. The AIDS Office was the linkage to our funding, so we had a very close relationship with the staff at the AIDS Office, and

probably would still recognize each other's voice if we called each other up, because we were on the phone so often together.

Hughes: Over what issues?

Martin: Funding issues. We would say, "We need this, and don't bother us with these little picky things." We had a great need for money, and they had a great need for detail. There were all kinds of challenges around funding and service delivery issues. We were all new at this, so we were all being advocates for our own group. So we had a very close working relationship with them.

The Department of Public Health nursing department had a lesser role, because we really to a degree took over the role of the public health nursing department. Most of the patients in the early days that we served were really sick. I mean, they didn't have time to go to the public health department nurses. Now, the public health department is starting its own home-care program. They've always had a home-care program, but it never grew before now. We received the funding for AIDS care, so they didn't take these sicker, terminally ill AIDS patients.

I think, with the changing reimbursement patterns and changing emphasis on utilization patterns, that some of that money will shift back into the department. If I was in [San Francisco Health Department Director] Sandra Hernandez's shoes, that's what I would think of doing. And I know she's thought about it.

A public health nurse representative came periodically to our patient care conferences and then met with our intake coordinator --I'm picturing her coming to our office on 30th Street. But over time, it just didn't happen much. I think what the public health nurses were doing was different. They discharged patients to us, but we didn't discharge too many patients to them, because people with AIDS didn't stabilize and get better.

That may be different now, but I don't think it's probably dramatically different. Most of the time, once somebody is sick enough to come into a home-care program, they continue to be sick. There is some stabilization, but they're deteriorating, unfortunately.

Hughes: Who referred your patients?

Martin: I would say the bulk of the patients came from San Francisco General Hospital, and probably from another pivotal group, which is now called the California Pacific Medical Center [CPMC] Medical

Group, where they see a lot of AIDS patients. Bob Bolan¹ just moved recently [to Los Angeles], but he had been a key physician here for many, many years, and was affiliated with CPMC. Paul Volberding and Don Abrams² were the two people that I probably had the most contact with, initially due to our relationship with SFGH, Ward 5B and Ward 86. After a while, we didn't have contact, because I wasn't involved at the clinical level and we didn't have so much need, but they probably were two key people in terms of how things developed and evolved.

The physicians, I would say in general, were from San Francisco General Hospital, and then community physicians. I'm not the best person to answer that question.

Hughes: How often would a physician be in contact with nurse about a given patient?

Martin: Well, for some patients as often as once a day; the norm was probably once a week. Every time a significant status change occurs in the patient, we're obligated to notify the physician. Now, if the patient has a change in medication needs, then we also have to get an order from the physician, and we can't administer it until we have an order. We can't get the medication until we have an order.

Hughes: A dynamic disease must place demands on both parties and require a quicker response than with most other average diseases?

Martin: Yes.

Hughes: And more often as well.

Martin: Yes, and that caused a great deal of stress and strain. Some physicians are very clear that it takes a lot longer to deal with an AIDS patient than it does any of their other patients. The patient takes longer in the office, and they get a lot of calls about the patient.

Hughes: Was the San Francisco General AIDS group easier to work with because they knew what kind of care AIDS patients required?

¹ Oral history with Robert K. Bolan, M.D., in progress in The San Francisco AIDS Oral History Series, phase 3, San Francisco community physicians.

² See the oral histories with Paul A. Volberding, M.D., and Donald I. Abrams, M.D., in the AIDS physicians series.

Martin: Well, Ward 86 would be easier for that reason, because it has nurse practitioners that essentially are in charge of the AIDS patients. They're the primary care providers. And then there are attendings [attending physicians] that are there as well. But the attendings are a fixed set of physicians.

San Francisco General as a rule is very difficult to work with, because you have to have orders signed, and the resident physicians rotate, because it's a teaching facility. And often it's a resident who signs your order, and you have to have an attending sign orders for home care. You'd get a verbal order from someone, and by the time you got the treatment order back, or it was sitting around, that person had gone on to their next rotation, so you couldn't get it signed--all kinds of complications like that.

So from a home care provider standpoint, dealing with San Francisco General at one level was the best, and dealing with them at another was probably the worst.

Hughes: Did that mean that in some cases patients were not getting the medication that they needed?

Martin: I would say that there weren't very many cases where patients didn't get the medication they needed. We may not have gotten the signed orders in a timely manner that were required from a regulatory standpoint. We may have had a verbal order that Dr. John Smith ordered this at such-and-such a time and such-and-such a place, and called it into the pharmacy. So we got the medication. But from a regulatory standpoint, the home-care provider has to have a certain set of documents in the patients medical record.

Hughes: And those were a long time coming.

Martin: Yes. Those were the technical problems.

Other Community Support Agencies

Hughes: Are there other organizations that we should mention in this web of community support that we're describing?

Martin: I would say that from an historical standpoint, the San Francisco AIDS Foundation, the Shanti Project, the AIDS Health Project, Project Open Hand are very significant. It's hard to know if Project Open Hand will become less significant over time. I don't

mean that food service isn't important; I think that Project Open Hand will have difficulty supporting itself over time, because it is a food service, and they probably don't charge enough.

Project Inform is a very important organization for providing information in the community, and an access point for people to gather information about treatments and experimental regimes. It's an information point.

Hughes: Did your program have a philosophy about alternative therapy?

Martin: There are two kinds of alternative therapies: experimental alternative therapies that are under a research project and are legitimate; and alternative therapies which might well be successful but don't meet regulatory requirements that we can then stand behind. Patients could choose to do those things on their own. We couldn't intervene.

A clinician (nurse or physician) might give you a different viewpoint on this. Val Robb at VNH of San Francisco might be a person for you to talk with. Val is an excellent clinician and has had a lot of experience. Mark Donnell at CPMC and Anne Hughes at San Francisco General would give you a good perspective. Anne hasn't done home care for a while, but Val and Mark really know home care and AIDS care.

Other linkages? Continuum HIV Day Service is cutting edge in adult day care delivery. They serve the frail, homeless AIDS population.

##

Martin: Continuum provides a natural continuum of ambulatory services, but the funding is limited. They are very highly recognized by the city health department and receive significant funding from it.

Hughes: Is that a new service?

Martin: No, it's been available since the late eighties, but it's only been the last couple of years that it's been positioned as a key component of the care delivery system. Continuum has a new executive director, William Glenn, who's a really terrific leader. Since he's come on board, I think they have made a mark. Before then, they struggled regularly.

There are other newer organizations. All the minority organizations play a very important role, but a different role. I have not been involved with those organizations, so I can't speak

to their real value or what impact they've had in the minority communities.

Patient Preference for Home Care

Hughes: What does being able to remain at home mean to an AIDS patient?

Martin: When given a choice, people say they want to stay at home. In fact, a Gallup poll was done several years ago, in response to the long-term care legislation sponsored by Claude Pepper and known as the Pepper bill. The poll indicated that something like 65 percent of people wanted to remain at home. Home care allows people to remain with their loved ones, and also to stay in an environment that is the most familiar and cost-effective for the individual; or, if they're not allowed to stay there, they're able to shift into a residential care setting where they're still able to have their loved ones come in and out as often as they want. Home care provides an environment that's supportive, caring, humane. It's the environment that people really want at the end of their life or in a very difficult period of their life.

So it allows the person to remain in control of their situation. If you're in a hospital environment, you're really not in control. If you're in your home environment, you don't have to open the door if a nurse comes. So it's a problem for the nurse, but the patient can make that decision. If the patient is not mentally impaired, it's just the best environment for them to be in. It gives them control and support and caring of family and friends, and a home care team coming in.

Impact of AIDS on Home Care

Hughes: One last question: Are you aware of ways in which having to deal with AIDS has changed home care?

Martin: This is a very personal belief: I think the advocacy that we have had regarding AIDS has increased insurers' awareness of the need for custodial care, and encouraged policy makers to realize that custodial care really isn't a bad word, that it is an important need that people who are chronically ill and debilitated have. So my personal bias is that all that arguing and all that lobbying and all those presentations that I and many others gave over the

course of many years on home care really did make a difference. And I have a very strong belief that they did.

There are people who would say, "We always knew this stuff." The Ryan White AIDS Care Act is a perfect example of advocacy around the disease that is focused on the community. It is meant to keep people out of the hospital, and it was designed on the San Francisco model.

So I feel like we did make a huge difference in what is ultimately accessible and will continue to be accessible, as insurers change what they think is necessary and look at lowering costs. They realize that custodial care is a lot cheaper than a nurse. We don't have to pay somebody \$100; we can pay somebody \$30. I did a lot of speaking to insurance companies, at their national meetings, and said, "This insurance coverage for home care is really what is needed." They were also educated about AIDS, a disease they had little knowledge of.

I really think we made a difference; it was worth it, and continues to be worth it. It's not over; it's just in different people's hands. I'm not quite as involved any more.

Hughes: Well, anything else you want to say?

Martin: I don't think so.

Hughes: Thank you for your time.

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The San Francisco AIDS Oral History Series

THE SAN FRANCISCO AIDS EPIDEMIC: THE RESPONSE OF THE NURSING PROFESSION,
1981-1984
VOLUME I

Helen K. Schietinger, R.N., M.F.C.C.

NURSE COORDINATOR OF UCSF'S FIRST AIDS CLINIC

An Interview Conducted by
Sally Smith Hughes, Ph.D.
in 1995



Helen Schietinger, mid 1980s.

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INTERVIEW HISTORY--by Sally Smith Hughes

Appropriately, Helen Schietinger is the subject of an oral history in the first volume in this series on AIDS nursing in the early years of the San Francisco epidemic. It is appropriate because she was the first nurse to work at the first clinic set up expressly to care for patients with Kaposi's sarcoma, a rare form of cancer which for unknown reasons was appearing in young gay men. When she assumed the position at UCSF in January 1982, the epidemic had only recently acquired a name destined to endure--acquired immunodeficiency disease or AIDS. Thus Schietinger could justly claim to be the first nurse appointed to an official AIDS position in the Bay Area and perhaps in the nation. The name of the clinic, the Kaposi's Sarcoma [KS] Clinic, reflects an early view of the San Francisco epidemic in which KS was perceived as its most visible manifestation.

Marcus Conant, a UCSF dermatologist with a private dermatology practice, established the clinic at UCSF in the summer of 1981 and immediately set about to hire a clinical nurse to "coordinate and implement an involved protocol of laboratory studies..." The studies were aimed at unravelling the etiology and progression of the syndrome of cancers and opportunistic infections which in San Francisco were initially seen almost exclusively in gay men. Conant also specified a preference for "an individual who is knowledgeable about gay life style in San Francisco and the Bay Area" and "comfortable working with homosexual male patients."¹ Conant's requirements reflect an early perception of AIDS as a gay disease and also the stigma attached to homosexuality, even in the relatively open city of San Francisco. Schietinger, with ten years of nursing experience in hospital and community settings, a degree in counseling, and her personal warmth and empathy, was a perfect fit for the position. Furthermore, her status as a lesbian made her particularly sensitive to the physical and emotional problems of young gay men afflicted with the new syndrome.

Schietinger provides an insider's view of the operations of, and her responsibilities in, the KS Clinic, which was the only medical facility in the Bay Area dedicated exclusively to serving people with AIDS until the opening of the AIDS Clinic at San Francisco General Hospital in January 1983. She tells of the medical, scientific, and social services which she and other AIDS "pioneers" set up in these earliest years of the epidemic before HIV had been identified. The handout which she produced in March 1983 for use by gay patients in the KS Clinic at UCSF and the AIDS Clinic at SFGH may be found in the

¹ University of California, San Francisco, Ambulatory Care Center, Clinical Nurse Job Description," July 9, 1981, interviewer's collection, courtesy of Helen Schietinger.

appendix. Schietinger's history of a clinic which was virtually eclipsed in the mid-1980s by AIDS activities at SFGH is interesting to compare with that of Conant's, whose oral history is in the AIDS Physician series.

The Oral History Process

We met in Schietinger's hotel room in San Francisco for two late-evening interview sessions on January 30 and February 2, 1995. Schietinger had come from her home in Washington, D.C. to be an organizer and moderator of the 7th National AIDS Update Conference running concurrently in San Francisco. Because of the cramped room, she sat on the bed, and I sat nearby, both of us occasionally referring to the documents on the KS Clinic which she had kindly brought from her home files. Schietinger took very seriously the task of setting down the history of the clinic, in part because none of its patients survive. She recommended that I interview Michael Helquist, whose partner was an early clinic patient, to obtain a layperson's perspective on what it was like to attend this clinic.

There was much more that Schietinger could have said about her work in the epidemic, which continues to this day. Because of the brevity of her visit and this project's focus on the first three years of the epidemic, discussion was limited to subjects associated with the KS Clinic. The reader is urged to review Schietinger's curriculum vitae in the appendix which suggests her many contributions to AIDS-related issues. The edited transcripts were mailed to Schietinger, who edited them lightly and returned them with further background documents.

Both Schietinger and Helquist mention in their oral histories that patients called her "Dracula" because of the large amount of blood she drew from clinic patients for research studies. In actual fact, she was loved and respected for her role as care giver and patient advocate and for her concern to ensure patients' physical, psychological, and emotional welfare. The reader will find evidence of these traits on page upon page of her oral history.

The Regional Oral History Office was established in 1954 to augment through tape-recorded memoirs the Library's materials on the history of California and the West. Copies of all interviews are available for research use in The Bancroft Library and in the UCLA Department of Special Collections. The office is under the direction of Willa K. Baum, Division Head, and the administrative direction of Charles B. Faulhaber, James D. Hart Director of The Bancroft Library, University of California, Berkeley.

July 1998

Sally Smith Hughes, Ph.D
Research Historian and Interviewer

Regional Oral History Office
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University of California
Berkeley, California 94720

BIOGRAPHICAL INFORMATION

(Please write clearly. Use black ink.)

Your full name Helen Kay Schietinger

Date of birth June 19, 1948 Birthplace Chicago IL

Father's full name Egbert F. (Tex) Schietinger

Occupation Sociologist Birthplace Weimar Tx

Mother's full name Ruth Evelyn Brock Schietinger

Occupation Housewife Birthplace Arkansas City, KS

Your spouse Donna Davis

Occupation Survey research Birthplace Jefferson City Mo

Your children None

Where did you grow up? Atlanta GA

Present community Washington DC

Education Masters degree in Counseling, Bachelors degree in Anthropology, Associate degree in Nursing

Occupation(s) Policy analyst, program development and evaluation, technical writing (in the fields of health care & AIDS)

Areas of expertise nursing, counseling, AIDS

Other interests or activities Bird watching; I volunteer as a support group facilitator for the Mauntner Project, an agency that provides support for lesbians with cancer

Organizations in which you are active Association of Nurses in AIDS Care, American Public Health Association, National Gay/Lesbian Task Force

INTERVIEW WITH HELEN SCHIETINGER

I EDUCATION

[Interview 1: January 30, 1995] ##¹

Schietinger: When I finished high school, I decided I needed to get out of the South, go back up north, and find a place where people weren't prejudiced. So I went to Oberlin College, because I thought that was where I'd find good people, which I did, but I also discovered that people are prejudiced everywhere.

I graduated from Oberlin with a bachelor's degree in anthropology in 1970, and then was actually very involved in the anti-war movement. But I also went back to school to get my associate degree in nursing [1973] in Atlanta at Dekalb College, because I found that my bachelor's degree in anthropology would only get me a job as a secretary out there in the real world. So I became a nurse.

After almost ten years of doing nursing, I realized that I wanted to be working with people in a more intensive way than I had been working with them, and that the emotional and family issues that were associated with chronic illness were not being addressed in the work that I was being paid to do as a nurse.

So I went back to school, to graduate school [at Sonoma State University, California], to get my master's in counseling, to get more skills to work with people. I really expected to continue nursing, with a master's in counseling, to work with families who were coping with a person who was chronically ill or had a catastrophic illness.

¹## This symbol indicates that a tape or tape segment has begun or ended. A guide to the tapes follows the transcript.

II THE KAPOSI'S SARCOMA CLINIC, UCSF

Nurse-Coordinator, Kaposi's Sarcoma Clinic, UCSF

Application and Hiring

Schietinger: I graduated from Sonoma State University in Sonoma County in 1981, and at that point, was looking for a job in which I could combine my nursing and counseling skills. I felt one of the places I could do that would be at UCSF, that maybe they had some research projects in which they needed nurses to interview people.

So I made contact with a friend of a friend who worked at UC in the nursing department. I called Angie Lewis¹ and asked her if she knew of any research jobs that needed interviewers. She said she didn't know of any, but there was an opening for a nurse-coordinator for a new clinic that was being developed for gay men that had cancer.

This was probably the fall of '81. I hadn't heard anything about this new disease, so that was the first I had heard of it. But it sounded very intriguing, and the fact that I'm gay made it doubly intriguing. I thought, if gay men were getting cancer, there would be a lot of issues that they'd have to deal with about their sexuality and their sexual orientation that would benefit from a sensitive ear.

So I applied for the job. Before I was interviewed for the job, I went to one of the KS study groups that was being held at UCSF. I remember distinctly walking away from that meeting of epidemiologists and physicians and public health people, being absolutely fascinated. And then I was a little horrified at myself at being so fascinated at this devastating medical puzzle. It was a combination of

¹ See the oral history in this series with Angie Lewis.

feelings of being fascinated and excited on one hand, and horrified and terrified on the other. Yet especially after I was hired and I began to work with the people who were coming to the clinic I saw how terrifying it was to the people who were actually coming down with the illness. The unknowns made it terrifying, as opposed to how fascinating it was to the researchers. But that's how I got to be involved in the KS Clinic.

Hughes: You began, officially anyway, in January 1982.¹

Schietinger: Right.

Hughes: And you say you had had some associations before that.

The American Cancer Society Grant, December 1981

Schietinger: Yes. It was probably in November [1981] when I attended that KS Study Group. I was disappointed that I was going to have to wait until January to start work.

Hughes: Was that a question of money?

Schietinger: No. I was working as a home care nurse--

Hughes: I meant in terms of the clinic, because I know Marcus Conant was trying to find money, and the American Cancer Society, of course, came through.

Schietinger: Right.

Hughes: But the money didn't actually arrive until December 1981.²

Schietinger: Actually, that may have been it. It may have been an issue.

Hughes: It was a very quick turnaround between the grant application and receipt of funding.

Schietinger: Absolutely.

¹ M. Helquist. What to expect at the KS Clinic. Coming Up! March 1983. (Hereafter, Helquist.)

² Helquist.

- Hughes: It was John Ziegler who had the connections with [Frank J.] Rauscher, who was senior vice president for research of the American Cancer Society. It seems to me he didn't even write a letter until fall.¹
- Schietinger: Good heavens. I didn't realize that.
- Hughes: To have funding come through within just a few months was amazing.
- Schietinger: Absolutely amazing, yes. And the fact that they could actually create this clinic that quickly was also pretty amazing. When I came, they were already seeing patients.² It was totally chaotic because there was no one coordinating the clinic, but the physicians were actually seeing patients.

Identifying Kaposi's Sarcoma Patients

- Schietinger: The attempt to identify patients who had this new disease was going on on a citywide basis. The physicians had compiled a list of patients who were hospitalized with any of a number of opportunistic infections or with Kaposi's sarcoma. When I was interviewed for the job, I know there was a list being made, but I don't know how many people were actually coming to the KS Clinic.³
- Hughes: I guess it was KSOI [Kaposi's sarcoma and opportunistic infections] at that point, wasn't it? Was it the work of the CDC [Centers for Disease control] to get the word out so that physicians had some standard by which to identify patients?
- Schietinger: There was no standard--well, maybe they had developed a standard. Certainly they were identifying gay men who had

¹ John L. Ziegler to Frank J. Rauscher, Jr., Ph.D., September 23, 1981. (John L. Ziegler papers, folder: AIDS-NCS grant, AIDS History Project, Special Collections, UCSF Library. Hereafter, Ziegler papers.)

² The clinic was scheduled to meet for the first time on September 21, 1981. (Marcus Conant to William Epstein et al., September 2, 1981. Conant's Kaposi's Sarcoma Notebook, 1981-2/82. Hereafter, KSN.)

³ As of December 4, 1981, the KS Clinic had eight patients. (Conant to Jay Becksted, December 4, 1981. KSN through 2/82.)

been hospitalized with life-threatening illnesses, men who had an unusual opportunistic infection. Kaposi's sarcoma was not diagnosed immediately in most people. The lesions had to be biopsied. Richard Sagebiel [UCSF pathologist] was the only person with the expertise to read the pathology slides to identify the KS. The lesions themselves in early stages of development for the most part did not look pathological.

It wasn't until the word got out and gay men were saying, "If you have a spot, you better go see your doctor." Then the community doctor would say, "Well, this looks like it might be something suspicious. You better go to the KS Clinic where they can do a biopsy." So early on, KS was not usually recognized in the early stage of disease. Most people got very sick with Kaposi's sarcoma before they were actually diagnosed with it.

Hughes: That, I believe, is true, because it's now known that the people that you were seeing in the clinic had full-blown AIDS.

Schietinger: Yes, exactly.

Hughes: How else could it have been recognized before the antibody test?

Schietinger: Yes.

Educating Physicians about Kaposi's Sarcoma

Hughes: Do you remember how the word got out to community physicians about how to recognize AIDS? Both PCP [*Pneumocystis carinii* pneumonia] and KS were not conditions that most physicians were familiar with.

Schietinger: Exactly. And they would have treated people for other things, unsuccessfully, before they got to the point of even being suspicious that this person might have something unusual. There were a number of physicians who had large gay practices who attended the KS Study Group. I have a feeling that the initial physicians (eg, Marcus Conant, Paul Volberding) actually had contacted the physicians--gay physicians in particular--who saw gay patients, and then had briefed them and given them clinical rounds to show them what kind of lesions to look for.

Relationships with Community Physicians

Schietinger: A lot of the primary care physicians in the gay community referred people to the KS Clinic.

They're the ones who, I think, felt somewhat betrayed when the KS Clinic didn't establish relationships with them and report back to them about what was going on with their patients. It took awhile for the clinic to be organized enough to send letters back and say, "Thank you very much for referring your patient," those professional courtesies that are actually supposed to happen.

Hughes: That responsibility landed on your desk when you became the clinic coordinator?

Schietinger: No. Marc Conant actually sent letters from his own office. I was the one who recognized the need for coordination of care. I would call the primary care physician about some issue that was going on with the person, and then they would grumble about not having heard anything about what was going on. So how would they know what to do with this patient, because they didn't know what was going on.

Hughes: So there was a lot of educating that had to be done one way or another?

Schietinger: Yes.

Hughes: Was that one of your functions, too?

Schietinger: No. Marc continued to provide clinical rounds by having patients come to the KS Study Group, to show the patients as examples for the physicians that came to that meeting. But there was this difficulty with communication between community physicians and the KS Clinic that didn't get resolved, I don't think, until after I left.

Hughes: Do I read into this that there was some tension between the community and university physicians?

Schietinger: Absolutely. There was tension.

Hughes: I assume that a community physician would refer a patient to the clinic where he would be set up for a treatment program

under the aegis of the community physician. Right? The patient was supposed to return to the original physician?

Schietinger: Right. Theoretically, that's the way it should happen. But people were receiving treatment through the dermatology clinic at UC, in which the KS Clinic was housed, and they were being treated for skin infections or whatever right there in the clinic. There was a whole array of physicians at the KS Clinic: there was a primary care physician, an internist, and there were oncologists. There was Paul [Volberding] and there was Don [Abrams] and there were dermatologists, and residents in the clinic, all of whom were treating the patient. The patient had a medical record and a UC chart.

The problem was that patients weren't being sent back to their regular community physician with recommendations for ongoing treatment; they were just being seen at the KS Clinic. The KS Clinic physicians were saying, "Come back in two weeks so we can see you." The follow-up happened in the KS Clinic. So patients had the sense that, The experts are here at UC, so this is where I will stay.

Evaluating and Studying Patients

Schietinger: Then there was a whole staging process for the patients.¹ The staging process really was a complete clinical history of the patient. They were collecting as much data as they could on everybody who came through the clinic. A medical history and physical were completed, and then a lot of lab work, and a lot of extra lab work--whatever might give them some hints about what was going on regarding KS and in the patient's immune system.

Hughes: Did the sort of data that you were supposed to be collecting keep changing?

Schietinger: No, it seemed as though it kept being added to. The type of lab work that was being collected was fairly systematic. For a few months, we were obtaining lymph node biopsies on anyone who had lymph nodes that were of a certain size.

¹ See: Kaposi Sarcoma Clinic. UC Departments of Dermatology-Oncology. Patient Protocol. February 1, 1982. (Ziegler papers, folder: AIDS--KS Patients.)

There were decisions after a certain point to stop doing things that seemed not useful. There was a continual review. I know that there was a review of what was useful to the physicians.

But all of this [laboratory work] was being billed as medically necessary. There was no research grant covering the costs of tests, although the physicians who worked in the clinic donated their time, and some of the labs which wanted specimens conducted the tests free.

I know that there was always an issue with the T-cell tests. They were very expensive, and the lab could not continue to do free tests. It was very difficult, I think, to justify the T-cell test. The lab was having a hard time covering the cost of doing the T-cell ratio. It wasn't being billed in many instances, and many of the insurance companies wouldn't accept it. So there was always the issue of payment, before there was research money available to do the research.¹

Laboratory Tests

Hughes: Was it Art Ammann's group, or Art Ammann himself, who was doing the T-cell studies?

Schietinger: The studies were being done in the lab itself.

Hughes: The immunology lab?

Schietinger: Yes. Ammann was in pediatric immunology, but it seems to me that Conrad Casavant was more involved with the T-cell tests themselves. And that lab was collecting data. They were keeping in a separate place the names of everybody that was being tested. As time went by, they also periodically provided T-cell testing for health care providers who had been stuck with a hypodermic needle, or health care providers who were simply working with AIDS patients. So

¹ The first NIH grant for AIDS research at UCSF was announced in May 1983; the first sizeable state grant was approved by the California legislature in July. (UCSF receives National Cancer Institute grant for A.I.D.S. Research. UCSF News/Public Information Services, May 12, 1983. (Ziegler papers, folder: AIDS--ACS grant); Randy Shilts. UC assailed for delay on AIDS funds. San Francisco Chronicle, August 25, 1983, p. 10.)

most of the people associated with the KS Clinic did have their T cells studied. I know I did.

The attempt to find ways of doing this research in the early days when there was no research funding and when nobody knew what was appropriate was very important, and it was very difficult. I can remember going over to the immunology lab and trying to talk them into doing a few more T-cell tests on some new patients.

The Patient Intake Interview

Hughes: You, I understand, did the intake interview.¹

Schietinger: Yes, right.

Hughes: With every patient that presented at the clinic?

Schietinger: Yes.

Hughes: Could you tell me what it consisted of?

Schietinger: I initially did a psychosocial assessment. I wanted to find out how the person was coping, what his social support network was, what his response was, what his needs for information were, and what his needs for support were. Then I also did as much teaching as I could, to let them know what was known at that particular time about this illness, and what would happen to them when they went through the KS Clinic, so that they could anticipate opportunities to ask questions, but also so that they would understand what was going to happen to them.

I did as much teaching as I could about nutrition and, if they were sick, what sorts of things they could do to make themselves feel better on their own, in terms of resting and taking plenty of fluids and all the basic advice you give someone who has the flu. But if someone knows that it's not the flu and that it's something new and scary, it's important to have someone validate that these are the things you can do for yourself, even though they're fairly straightforward. You take aspirin for fevers and chills,

¹ Helquist, March 1983.

and if you need to sleep, you sleep, and you take lots of fluids, and that sort of thing.

Patient Anxiety

Hughes: By the time a patient had gotten as far as the KS Clinic, he knew it was serious, didn't he?

Schietinger: Right.

Hughes: So did most patients come in frightened?

Schietinger: They came in very frightened. As time went by, people came in having noticed a lesion, but with no other symptoms of AIDS. So as we saw more people with early Kaposi's sarcoma, there was the anxiety that's attached to "something might be wrong." With later stage disease, people felt a sense of relief that somebody might be able to tell them what's been going on for the past few months that they haven't understood. With early KS, people felt terrified that this harmless-appearing spot might be KS, which meant a deadly disease.

So both of those kinds of reactions were happening, but the newly diagnosed person with KS but without other symptoms of AIDS was much more common as time went by. Those people were the ones that had the most anxiety at having a biopsy and having to wait two weeks for an answer. Then I would get phone calls in between visits to find out whether the biopsy results were back. Could they come in this week?--no. And I would call the lab and find out if they had done this particular biopsy, and call the individual back and say, "Well, we don't have an answer, so you'll have to wait another week." That interim waiting time, I think, was the most anxiety-laden for people.

One of the things that was also happening was these all were gay men who were coming into a medical setting in which they were going to be asked a lot of questions about their sexual habits. I tried to prepare them for that a little bit. I tried to normalize the situation by encouraging them to bring their lover, if they had a lover, or to bring a friend, to try and feel somewhat comfortable in this medical setting.

Confidentiality Issues

Schietinger: I actually was not comfortable with the fact that an extensive sexual history was being taken and put into people's medical records. I suggested that we keep separate records. Those questions were not in my mind medically necessary for the benefit of this patient and should not be in their medical file, which I know full well is very available to many of the people who work in the university system.

Hughes: Were you thinking of possible repercussions, or were you thinking invasion of personal privacy?

Schietinger: Invasion of privacy. I was more concerned with the integrity of this individual, who was already having his privacy invaded to a tremendous extent. The staff was suddenly aware that these people--these people, just the very terminology, "these" people, these new people that had AIDS--were possibly contagious. The infectious issue was very frightening to people, and one of the early things that I had to do a lot of was talking to staff, and going through what we knew about this new disease regarding transmissibility.

The other thing was that people who had not known about gay men's sexual habits were suddenly learning about very esoteric sexual behaviors that never would have occurred to them before. In the early days, in 1982, the CDC had done their case-control study in New York City, where they had interviewed extensively fifty people with AIDS and 120 controls, and had identified fist-fucking as one of the potential risk factors.¹ Even the term fist-fucking was new. It was something that was suddenly being talked about in straight medical settings, but most of us had never heard of fist-fucking.

¹ The CDC, in collaboration with investigators in New York City, San Francisco, Los Angeles, and Atlanta, began the case-control study in October 1981. Fifty patients with KS, PCP, or both were compared with 120 matched homosexual male controls from sexually transmitted disease clinics and private medical practices. (H.W. Jaffe et al. National case-control study of Kaposi's sarcoma and *Pneumocystis carinii* pneumonia in homosexual men. Part 1, Epidemiologic results. Annals of Internal Medicine 1983, 99:145-151; M.F. Rogers et al. Part 2, Laboratory results, *ibid.*, pp.151-157.)

My assumption that there would be a lot of generalized negative response to all gay men, based on this new information that people were learning, made me particularly sensitive to the possibility of people flipping through other people's files. The sexual history was supposed to be taken in code. There were certain terms that they used codes for in the medical histories. Marc justified this being a part of the routine medical procedure in the dermatology clinic because most private information was in code, and that people wouldn't know what it meant if they read it.

Hughes: Why did he think it was necessary to have it in the record?

Schietinger: He thought it was important to get as much information as possible, because maybe in an aggregate form, these data would tell us something. These attempts to gather as much information as possible made me uncomfortable about the way that the research was being done at the KS Clinic. The reason that I went to the human subjects committee [UCSF Committee on Human Research] and began the process of developing an informed consent and a research protocol that would be official was to make sure that people were actually aware that this was research, which it was. But it was informal research in the very beginnings of the epidemic, and the physicians just were more concerned with getting the data gathered than being stymied by the slowness of the human subjects committee. I'm sure that their relationship to the IRB [Institutional Review Board] had to do with that.

Patients as Research Subjects

Hughes: When it became clearer to people that some of the procedures were strictly for research purposes rather than for diagnosis or treatment, did they hesitate to comply?

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Schietinger: When people were given the opportunity to say no to a biopsy, for example, on the basis that it was not going to provide information that would be useful for their medical situation, they always said, "Do it anyway. I want to help. If there's anything I can do that will be useful in finding out something about this disease, I want to do it." Over and over again, I as the patient advocate being protective of the patients, either in the context of research or in the

context of media coverage, found that although ethically it's very important for people to give that consent, in this epidemic, people always gave consent. They were always willing to provide information that was requested.

Hughes: Do you have an explanation for their willingness?

Schietinger: Well, I think it had to do with altruism. It was always in the context of, "If I can help someone else, if I can find meaning in this disease, make it meaningful by having my experience be useful to someone else, then I want that to happen." That was particularly true in terms of providing information; that was something that was important to people.

Hughes: I'm not trying to take away the altruism by making this suggestion, but perhaps when somebody is going through a gruesome experience, it would help a bit to think, Well, maybe this will help somebody else.

Schietinger: I think that's probably true. Absolutely. Oh, yes, and I think that giving the disease meaning, or giving the whole experience meaning, by being able to contribute also is certainly self-serving. Because the despair of having your life cut off is a pretty gruesome thing to have to deal with.

Hughes: I would think that there would be a certain comfort involved in coming to a clinic where at least there was a procedure and a ritual and concerned people.

Schietinger: Exactly, that's very true. And a place where people have seen this condition before.

Hughes: Yes, knowing you're not the only one who has it.

Schietinger: Yes.

There's another aspect that I think early on became very important. There are times when people with any disease need connection with someone who has the same disease. When people came to the KS Clinic was usually not when they wanted to talk to other KS patients. But they did very much want to have that connection at some point, even in the early parts of the epidemic when we didn't have a name for the syndrome and no one really knew what was happening; they just knew people were dying. They wanted to know from us at the clinic, "Do I have this?"

Bobbi Campbell: Patient Activist

Schietinger: An important thing that happened at the clinic was that one of the early patients, Bobbi Campbell, was one of the first AIDS activists. He wanted to make himself available to other patients so that they could meet someone who was still actively working and had been diagnosed with Kaposi's sarcoma, and clearly had this disease, but who was well. He felt very compelled to help by making himself available.

Bobbi was also an educator. Bobbi got copies of the slides that Marc had taken of the lesions on his feet. I gave him the slides so that he could get photographs made of them. Then he made posters out of them and put them up in the window of the pharmacy down in the Castro District, so that other men could see that and, if they saw that these lesions looked familiar and they had some like it, that they could come into the clinic and get them dealt with.

So the need for having the disease normalized in some way, I think, is really relevant.

Hughes: Was there such a thing as an average patient in those early days, in terms of the sorts of symptoms and opportunistic infections that were being seen?

Schietinger: Good grief. That's an interesting question. My first impulse is yes, but then I can think of all the exceptions. I think of all the people who were far from average. But the clinic itself really was seeing a lot of people with early Kaposi's sarcoma.

Patients with Opportunistic Infections

Schietinger: I think that the word had been put out, and the people who were coming in with opportunistic infections were so sick that they had to be hospitalized and were being treated in various hospitals around the city by their primary physicians. I think probably there was much consulting going on over the telephone with Paul and with Marc, that those people were being included in the network that Selma Dritz (at the San Francisco Health Department) was collecting information about, but clinically they were being treating by infectious disease docs.

There probably was something else happening that I wasn't even aware of. I'm sure that the infectious disease docs at UC had a whole network of referral systems and consultations that they were doing somewhere else besides the KS Clinic.

Marcus Conant's Role

Hughes: Interesting that there was never a PCP clinic.

Schietinger: Right, that's true.

Hughes: Why was it? Is it the fact that it happened to be Marcus Conant, a dermatologist, who heard of the first KS case in the city, and--

Schietinger: I think he would have established a KS clinic whether he had heard of the first case or not. I think Marc Conant was really the one that had the most concern, that saw that something needed to be pulled together, that people needed to be looking at things systematically.

What I find interesting is that the whole epidemiological thing gravitated around the KS Study Group, as opposed to being at the health department. That Selma Dritz came to the KS Clinic. This was the place where the experts who were concerned about this disease did their brainstorming. And it was Marc's announcements about the next KS Study Group or whatever, his collection of names for the mailing list, that was the catalyst for something to happen in San Francisco. I think it was Marc, and his concern, and his dynamism, that made it happen.

Hughes: And what about his connections with the gay community? Was that a factor, too, in the early success of this venture?

Schietinger: Possibly. Certainly his connections with the gay physicians. I know that one of the people whom he worked with very closely in terms of founding the KS-AIDS Foundation¹ was Bob Ross, the editor of the Bay Area

¹ The foundation was founded in 1982 by Conant, Franklin Jacobson, and Richard Keller as the Kaposi's Sarcoma Research and Education Foundation. Bob Ross was one of several board members. The Foundation subsequently had several different names, including the AIDS and KS Foundation and the San

Reporter. Bob Ross was on the board, and he was one of the important people in the gay business community. I'm sure that Marc made those connections within the gay community that were very useful in the beginnings of the epidemic.

Hughes: Was your perception of Dr. Conant that he was functioning as a physician who happened to be gay? It seems to me that if it were reversed, if he were a gay man who happened to be practicing medicine, then issues such as consent and invasion of privacy and those sorts of things would have been foremost in his mind.

Schietinger: Yes, I think that's true.

Hughes: He was functioning as a physician.

Schietinger: Yes, very definitely.

Hughes: So the group needed people like you who were concerned about such issues?

Schietinger: They probably didn't think so, but I did. [laughter]

Hughes: All right. The patients, the people with AIDS, needed people like you.

Schietinger: Yes.

Hughes: I think when you're engaged in a medical emergency, you do what you're trained to do.

Schietinger: Exactly. Being expedient and getting the information as quickly as possible was primary to the physicians. And that had to do with saving lives as much as with how interesting research was. Certainly the concern with figuring out what was going on so that they could do something was really important.

Francisco AIDS Foundation. For details, see the oral history with Marcus A. Conant in the ROHO series, The San Francisco AIDS Oral History Project: The Medical Response, 1981-1984. Hereafter, the AIDS physicians oral history series.

Theories about Etiology

- Hughes: When you came on as nurse-coordinator in January, 1982, can you remember what the prevalent theories were about the cause of this disease?
- Schietinger: I seem to remember that essentially in the medical community it was already accepted that it was a sexually transmissible disease, that there was no theorizing about that anymore.
- Hughes: So poppers had dropped out of the discussion?
- Schietinger: Well, there was still a question as to whether there were cofactors, that poppers might be a cofactor that was the catalyst to make someone have a particular opportunistic infection or that reduced the immune system enough so that whatever was contagious, stuck. There was a great deal of interest, especially among the epidemiologists, about particular behaviors that would be cofactors. Fist-fucking and anal intercourse and water sports and all of the things that could have been various means of transmission were being looked at pretty seriously.
- But I think most people assumed that it was a sexually transmissible disease. I remember being very comfortable with the hepatitis B analogy, and that we needed to not be exposing ourselves to blood and to body fluids, but that it was pretty obvious that, whatever this was, it wasn't transmissible through the air. This was something that I worked very hard to convey to other health providers, using the epidemiology as an argument for why it was sexually transmitted, and that other people around gay men were not getting this disease from them.
- Hughes: Was that something that you had figured out on your own, by observation?
- Schietinger: No. I think this was a rationale that was already being used by--I want to say the epidemiologists--so it may have been coming from the CDC. The CDC had already been in New York finding injecting drug users and gay men with the disease, seeing that it was in these two groups of people, and knowing that what they had in common was blood transmission and sexual transmission, and it looked very much like hepatitis B to them. So I think that was given to me; it had already been established when I arrived.

One of the things I always go back to is the importance of the CDC having identified injecting drug users with the disease early on. It was identified as a new disease among gay men in the early publications, but in fact it was known, certainly by the fall of '81, that it was not just a disease of gay men. So the identification of this disease as something that was happening in gay men and therefore it had to do with their sexual behaviors was not realistic. It was specious.

Hughes: Yet it continued to be perceived of as a gay disease.

Schietinger: Exactly. That was one of my biggest struggles. That was one of the reasons that the talk that I gave at the National Lesbian/Gay Health Conference in Houston in the summer of 1982 was written the way it is. I needed to make it very clear as a health provider as well as as a lesbian, as a member of the gay community, I felt threatened by people's potentially negative reactions to the gay community in general. It was very important to me to make it clear that AIDS was not a gay disease. But I was just talking to various groups of people, and was not the one who was publishing the articles.

There was a minor theory that the buildup of various assaults on the immune system might have caused this syndrome. Actually, there were even some people in the medical community, come to think of it, who still weren't convinced it was contagious, that it actually was a--

Hughes: Immune overload.

Schietinger: Immune overload--that was the theory. I had forgotten about that, but there were those who felt that that was what it was. But I can remember assuming that it was infectious from the very beginning, and that it was new, and therefore probably a new disease syndrome.

Hughes: Originally there was only one risk group, namely homosexual men.

Schietinger: But the CDC had identified injecting drug users from very early in the epidemic.

Risk Groups

Hughes: As time went on, it became obvious that other groups were becoming infected. It became the famous four H's for a while.¹

Schietinger: Exactly.

Hughes: Was that something you were comfortable with?

Schietinger: Well, it was. I didn't think of the political ramifications of Haitians being identified as a risk group. I was one of the people who, in giving my talks, listed the four risk groups. But I also was very happy to begin the shift of focus to risk behaviors, and to identify that there are many homosexual men who do not engage in the behaviors that would expose them to this disease. That became a relief to me in my attempt to separate out the issues, and to enable the gay men's community to deal with sexual transmission as the issue related to AIDS, not sexual orientation.

Hughes: Are you saying that it wasn't clear in the beginning that the fact that you were gay didn't necessarily predispose you to this disease? Rather, it was what you did as a gay person? That that distinction wasn't initially made?

Schietinger: Yes. And in fact, initially there was no distinction between gay men and lesbians. In the mind of the public, all male and female homosexuals were at risk. They didn't necessarily think about the differences. Actually, the genetic predisposition issue was being looked at in the labs, too. They were doing HLA [human leukocyte antigen] typing on people. There were Haitians, who were a national group, coming down with the disease. Was there something about them that was genetically distinctive? I think that was muddy in people's minds, actually, and it was something that early on I felt needed to be clarified. It would be interesting to look in the GMHC [Gay Men's Health Crisis] booklet and see how they identify it in 1982, as they are coming out with the first literature on AIDS for the gay men's community.²

¹ Homosexuals, heroin users, hemophiliacs, and Haitians.

² Lawrence Mass, M.D., in the GMHC booklet, which Schietinger kindly gave the interviewer, states under the heading, "Who is at risk?": "Despite the growing body of informed speculation about such potential risk factors

Hughes: Was there some event that switched people's thinking towards the idea that the disease was linked to behavior rather than the fact that you happened to be gay? Some of the epidemiological work, in which sexual practice was studied, could have led in that direction. For example, receptive anal intercourse.

Schietinger: But that was really only eventually. It was a long time down the road before there was really enough epidemiological evidence. The key event was the identification of the virus, I think. The fact that finally this virus was identified as the agent that was the underlying cause of the immune deficiency, even if there were a number of behavioral practices, or immune overload, or all those other theories that might have contributed to transmission of the virus, as well as to increased vulnerability of the immune system.

Before that, there was such a muddy confusion about what constituted safe sex. Later the term safer sex was applied, because nobody was willing to commit themselves to something being safe sex. But it was very muddy at the very beginning. I can't think of any event besides identification of the virus that helped make the shift from the danger being what you did rather than who you were. I remember the denial on the part of the blood banking people, that there should be something done about transfusions.

Hughes: Remember Art Ammann's baby?

Schietinger: Yes.

Hughes: In December, 1982, it was learned that one of the donors who had contributed blood used in the baby's multiple transfusions for Rh disease had come down with AIDS. It was one of the cases precipitating the problems with the blood bank people. Dr. Ammann believes that you really had to

as frequent sexual encounters with many partners, whatever causes AID [sic] remains unproved and unknown. This speculation includes the possible involvement of sexually transmitted diseases such as hepatitis, herpes in several forms, gonorrhea, syphilis and amebiasis. It also includes the use of such drugs as poppers (amyl and butyl nitrite) and marijuana. As Gay Men's Health Crisis stated in its previous letter to the gay community: "Unsettling though it is, no evidence exists to incriminate any activity, drug, place of residence or any other factor, conclusively, in the outbreak facing us.'" (AID [sic]: Acquired Immune Deficiency. G.M.H.C. Newsletter, no. 1, July 1982.)

have your head in the sand after that if you didn't think that an infectious agent was involved.¹

Schietinger: Oh, absolutely.

Hughes: Do you remember that baby being a real source of discussion?

Schietinger: Yes. But the babies that I remember best were the babies of the injecting drug user, whose immune deficiency he identified, but originally found very difficult to attribute to this new disease. I don't know if he talked about that.

Hughes: Yes, he did. He tried to work out complex genetic explanations for their immune deficiency--anything but AIDS.

Schietinger: Right, exactly. That's what I remember.

You're probably right. My recollection is that very early it was pretty clear to the experts that I was hearing from that this was a transmissible disease and that it was not contagious by air--something like hepatitis B. Probably it had to do with that event. Somehow, that was easier than the injecting drug users in New York, with their messy behavior. It was a cleaner association.

Fear

Hughes: What was happening to levels of fear during the confused period where the etiology could be any number of things?

Schietinger: And nobody thinks about contagion.

I seem to remember not too much fear in the dermatology clinic among the regular staff in the early days. They weren't afraid of the patients. And the staff when I would visit an inpatient didn't seem to be too concerned. They really didn't know what this was. In 1982, the fear wasn't there so much. When there was an infectious agent identified, then people became very frightened.

¹ Jean L. Marx. Spread of AIDS sparks new health concern. Science 1983, 219:42-43 (January 7, 1983). See also the oral history with Arthur J. Ammann in the AIDS physicians oral history series.

Hughes: You mean when the virus was identified?¹

Schietinger: Yes, when the virus was identified.

Infection Control

Establishing Procedures

Schietinger: I collected blood from patients as part of my job, and one day I went over to San Francisco General to draw blood from a hospitalized patient. I knew I shouldn't sheath the needle after I had drawn blood. I knew that I had to get the syringe and the needle out to the medicine cart where the nurse was passing meds [medications] on the floor. But nobody else seemed to be concerned about how I was going to do that. There was no receptacle at the bedside, in other words.

So I walked out and disposed of my stuff and went back to my office and called the infection control nurse, whose name is Grace Lusby,² and told her my experience. I said that I was concerned, because there needed to be a way of making sure that nurses didn't have to re-sheath their needles. There was a place that you dropped the syringes on the medicine cart, but it wasn't a closed container, and there was something about it that was just very wrong and dangerous.

She said she had been fighting with the administration for months, trying to get them to invest in unbreakable receptacles that could be put at the bedside. She said that

¹ In 1983, Luc Montagnier's group at the Institute Pasteur suspected a virus which they named lymphadenopathy-associated virus (LAV) to be the cause of AIDS. In April 1984, Margaret Heckler, U.S. Secretary of Health and Human Services, announced that the French group and a team at NIH led by Robert Gallo had isolated the causal virus, later named human immunodeficiency virus (HIV). (F. Barré-Sinoussi, J.-C. Chermann, et al. Isolation of a T-lymphotropic retrovirus from a patient at risk for acquired immune deficiency syndrome (AIDS). Science 1983, 220:868-871; R.C. Gallo, S.Z. Salahuddin, et al. Frequent detection and isolation of cytopathic retrovirus (HTLV-III) from patients with AIDS and at risk for AIDS. Science 1984, 224:500-503; Randy Shilts. And the Band Played On: Politics, People, and the AIDS Epidemic. New York: Penguin Books, 1987, p. 450-451. Hereafter, Shilts.)

² See the oral history with Grace Lusby in this series.

I embarrassed her into bringing up the issue again. She finally found a cheap solution.

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Schietinger: Until there were actually containers manufactured, red bottles for syringes, Grace arranged for nurses to use leftover Clorox bottles that they put at the bedside and labeled in very large letters. But in the early days, there was not enough fear, and then very quickly, there was too much fear. Both of those things were very problematic.

Hughes: What were you doing about infection control?

Schietinger: I was very sloppy.

Hughes: What was the protocol when you arrived at the clinic?

Schietinger: I don't believe there was one. I don't know. [Pause] People may have been wearing gloves to draw blood. I think people knew they didn't have to wear gloves to touch lesions or anything like that. There certainly was no overreaction in the clinic. Nobody was gowning and masking to go in and talk to patients. But in terms of gloves or needle re-sheathing, I don't think there was an official protocol at UC at that point.¹ I was not re-sheathing needles, but I was carrying around a needle box with me, a little box that you clip off the needle with. So I would draw blood, and then I would put the needle in the clipper and clip it, and then I would put the syringe into another container.

Hughes: Was that something that you on your own decided to do?

Schietinger: That was pretty standard procedure. I think that was something that was done all over the hospital. Everybody had needle-clipping things on their trays for venipuncture.

¹ On November 5, 1982, the CDC published "interim suggestions...to guide patient-care and laboratory personnel" in contact with AIDS patients or clinical specimens. By February 1, 1983, and perhaps earlier, SFGH had instituted "certain precautions to protect individuals working with [AIDS] patients." (Acquired immune deficiency syndrome (AIDS): Precautions for clinical and laboratory staffs. MMWR 1982, 31:577-579; Mary Anne Johnson, W. Keith Hadley. Inpatient isolation procedures for patients with Kaposi's sarcoma and other acquired immunodeficiency syndromes. February 1, 1983. AIDS Resources Center Archives, Ward 5A, SFGH, unlabeled off-white file box.)

Hughes: Was that the hepatitis B heritage?

Schietinger: No, that was to break needles so that injecting drug users wouldn't steal them out of the garbage can.

Hughes: Nothing to do with infection--

Schietinger: Nothing to do with infection.

I think it must have been months after I was there, I noticed there was dry blood all over the top of my little container that you clipped the needles off with. There was this dry blood lying around. And here I was, teaching other nurses that they shouldn't touch blood, and they should wear gloves to do venipuncture, and I had drops of dry blood all over my venipuncture container, and--

Hughes: And what kind of an instructor were you!

Schietinger: Yes, really. [laughter] I think at that point, I realized how sloppy I was being. I was not being worried about things that I should have been noticing.

Patient Reactions

Hughes: Was any part of this casualness, if that's the right term--

Schietinger: Yes, it is.

Hughes: --due to a wish not to upset the patients? Many patients were probably pretty frightened when they came to the clinic. If they were confronted by staff gowned and gloved and obviously not wanting to touch them skin to skin, that wouldn't have made them feel less afraid.

Schietinger: That's very true.

Hughes: Were you concerned not to further frighten the patients?

Schietinger: [Pause] No, I don't think so. I don't think I had any problems putting gloves on to do the procedures that I felt I needed to use gloves for. Some nurses argue that they don't want to wear gloves because they feel that will make the patients feel like they are anathema. But I guess I was always making the point to touch people, and to establish

that I accepted them and wasn't afraid of them, so I didn't have that problem.

I did have the problem with the patients with *Pneumocystis pneumonia* on ventilators in ICU [intensive care unit]. They had people masking and gowning to go in and see them, in the early days at UC. I believe we were supposed to do that to go in and talk to patients. I think I did feel uncomfortable with that, because it was not reasonable to me. And at the VA hospital, they were doing that for years after it was appropriate. It just made me angry. It wasn't until I went in without a mask and a gown on and upset the patient, who had been told that they were for his own protection, [laughter] that I realized that I couldn't win. A protocol is a protocol, and if you don't follow it, then you're going to upset somebody.

Hughes: San Francisco General thinks of itself as being in the vanguard of infection control.

Schietinger: Absolutely. They are.

UCSF Task Force on AIDS

Hughes: In 1983, the UCSF Task Force on AIDS, headed by Merle Sande, issued the first detailed infection control guidelines for AIDS.¹ Do you remember much about that?

Schietinger: Well, I remember the task force, and I remember there was this group of people having all these meetings. But by the time they had made official protocols, the infection control nurses who were dealing with the areas of patient care had already established what was appropriate and were implementing it. So I want to make a separation between practice and policy on that level, because it was all fine for Merle Sande, as the official person, to christen the protocol, but he wasn't the one who initiated appropriate procedures. That task force had Grace Lusby on it and other

¹ David Perlman. UC hospitals' guidelines on AIDS cases. San Francisco Chronicle, June 3, 1983. The guidelines were later published: J.E. Conte, et al. and [UCSF] Task Force on the Acquired Immunodeficiency Syndrome. Infection-control guidelines for patients with the acquired immunodeficiency syndrome (AIDS). New England Journal of Medicine 1983, 309:740-744. Also see the oral history with Grace Lusby.

people dealing with infection control who had been teaching the staff on a day-to-day basis from 1981.

Grace had already dealt with all that stuff by the time they actually came up with their protocol. She actually had already dealt with it by the time I called her and said, "What's happening here?" It's just that the response of the hospital administration had been lax, so the appropriate materials weren't there for nurses to practice what they had already been taught.

Hughes: So [Sande's] infection control committee formalized what already was being practiced?

Schietinger: Yes.

Support from UCSF

Hughes: Please describe your relationship with the university administration.

Schietinger: Well, I felt very cut off from the university. My relationship with the university was not a friendly one, I think. I was on staff; I was an employee of the university, but I also was on a short-term contract, because I was funded by this six-month grant. My position got extended, but it was always funded by soft money, so I was always considered peripheral.¹

The critical issue was that the KS Clinic was not a regular clinic of the university. For example, I approached my administrator, saying that there was a need for a social worker, that people coming to the KS Clinic needed to have assistance with applying for various benefits; they needed to have some help from a social worker. I was told that we couldn't have a social worker, that the KS Clinic was not making money for the university; it was not an official clinic. They told me that if they had their way, if I was actually a clinic staff person, then I would be assigned to be in charge of a number of clinics. I would never have the

¹ When the American Cancer Society grant supporting Schietinger's position as nurse-coordinator expired at the end of six month's, support shifted to State of California funds distributed by the Universitywide Task Force on AIDS.

luxury of having just the small patient load that I was in charge of.

So I didn't feel supported by the university, and I didn't feel that the patients who came to the clinic were supported by the university. It was a very different-looking clinic than what eventually evolved at San Francisco General, the AIDS Clinic. The difference was that there was extra funding from the city at San Francisco General to provide the additional staff to meet the complex needs of the patients.

Social Services

Hughes: As you explained to me off-tape, if you look at patient care as a spectrum, what the KS Clinic was able to do was only a very small part of that spectrum, which when the AIDS Clinic at San Francisco General was up and running, it could encompass to a greater degree.

Schietinger: Exactly.

Hughes: Funding was the bottom line?

Schietinger: It was. It was funding. And it was also the access to volunteers. But I think primarily it was the funding that enabled there to be additional staff, and the funding that was provided to the Shanti Project, so the Shanti Project could train and supervise volunteers that were then available to the AIDS Clinic. That was part of the evolution of services that didn't exist, of course, in the very beginning.

Hughes: Yes, but the perception of the need for social services seems to have come very early.

Schietinger: Absolutely.

Hughes: And that was because of what patients themselves were saying in the course of the intake history? You became aware of insurance problems, home care problems, that sort of thing.

Schietinger: Right.

Hughes: It became obvious that this syndrome wasn't just a hospital problem? It wasn't something you could give a few tablets

for and send somebody off, and everything else would be all right.

Schietinger: Right, exactly. It was very difficult to function in the context of the KS Clinic in the ways that the patients came to expect, because there was nothing else at that time, and because they perceived this as being the place where the experts were that knew how to take care of them. They didn't want to go back to their primary care physician who had sent them there because he or she didn't know what was going on.

The Clinic's Limitations

Schietinger: But in fact, the clinic happened once a week. It was really only set up to deal with a certain number of people at a time for certain reasons: to stage them, and to follow them prospectively as they were either receiving treatment elsewhere or being followed by an infectious disease doc or other specialist. But it was not established to provide their basic medical care, much less meet their emotional needs and that sort of thing.

Hughes: Did patients come hoping that those needs would be taken care of?

Schietinger: Yes. They came with lots of questions, and I spent a lot of time with them when people would come to the clinic. At first, on Thursday mornings, I found myself sitting in the hall, working with people who had come. Then I actually began having people come in at another time of the week to do intakes, because it was impossible to do what needed to be done on the morning of the clinic. So I got people to come in prior to their clinic appointment, and I began filling out intake sheets on them and doing the history. That was in reaction to how impossible it was to do everything that needed to be done at the clinic time.

It finally got to the point where people were actually being seen by two or three different physicians on the morning of the clinic, and so my access to them was limited, because the physicians were each examining them for various things. I had people come in to my office during the week, so that I could meet with them and deal with their issues. Even then I was not able to help them with the filling out

of forms, such as applying for Medicaid, which a lot of people did have to do.

Hughes: Because you didn't have the time?

Schietinger: I didn't have the expertise; I didn't know what to do. I just didn't know about these things.

The AIDS Clinic at San Francisco General Hospital

Schietinger: It was such a relief when the AIDS Clinic at San Francisco General got established, and there was a social worker there who made sure that people had access to the Medicaid eligibility worker. These were services that were there at San Francisco General that didn't exist at UCSF, or maybe did, but we just didn't have access to them.

Hughes: So it was a relief to have services available at San Francisco General?

Schietinger: It really wasn't a relief at first, because I felt betrayed. I felt as if this group was going over there to form this other clinic that was--not in competition with us--but was just taking patients away. Paul was going over there and setting up a new clinic, and he was going to continue to come to the KS Clinic, but this whole new thing was happening over there. My first reaction was a feeling of betrayal, that this shouldn't be happening. It wasn't until I saw what was being developed over there, and I realized that the city was actually making funding available for excellent staff, that it was real clear that that was a terrific advantage.

Hughes: Did it occur to you that this could have happened at UCSF?

Schietinger: Oh, yes.

Hughes: UCSF was where it started--

Schietinger: And this was where I felt it should stay. I wasn't involved in whatever discussions and strategy sessions happened to make Paul make that move.

Hughes: Was it a discussion point with Marc Conant?

Schietinger: I really don't know. If it was, I wasn't aware of it. My guess is that he refused to leave UCSF, that he wouldn't go over to this new clinic. My guess is that he was established at UCSF; that was where his office was,¹ and the clinic that he had set up. I don't know what happened in all of that. I just know that it felt really sad at the time.

UCSF and Homosexuality

Schietinger: There was an attempt at a later time to set up at UCSF an AIDS clinic--excuse me, it was not an AIDS clinic, it was the Adult Immunodeficiency Clinic.

Hughes: Quite deliberately so named to avoid the term AIDS.

Schietinger: Absolutely. It was real clear what couldn't happen at UCSF, as history evolved. And I should have known at the time I couldn't expect it to be a supportive environment for the gay staff.

Hughes: What was behind that lack of support?

Schietinger: Well, I never was on the inside of UC, so I don't understand the workings of it. I think it's a homophobic institution, frankly. But that's a very superficial look at it. I know that it wasn't a safe place to be "out" for most of the gay staff there. Angie Lewis was very courageous in identifying herself as a lesbian and going to visit patients in 1981, to tell them that she was a lesbian so that they would know that there was somebody there who was gay. All the staff around them knew that these patients were gay. Most of the gay staff did not self-identify, I don't think, even to the patients.

Hughes: But you did.

Schietinger: I did, absolutely.

Hughes: It was an element of the job description for clinic nurse-coordinator.

¹ Conant's dermatology practice is located a block from UCSF in a private medical building where many UCSF faculty members have private practices.

Schietinger: I didn't realize that. [tape interruption]

I made it clear in my interview that I was gay, and that I wanted them to know that I was a lesbian.

Hughes: [reads portion of job description] "Prefer an individual who is knowledgeable about gay life style in San Francisco and the Bay Area."¹ So it didn't necessarily mean that an applicant had to be lesbian or gay, but it certainly did not close the door.

Schietinger: Yes, exactly. That's good.

Hughes: I wonder who wrote the job description--it was probably Marc Conant.

Schietinger: I think so.

Hughes: "Supervisor, Dr. Marcus Conant," is at the top of the job description.

More on Conant's Role

Schietinger: One of the residents interviewed me and made the decision to hire me. Van Fletcher was the dermatologist who was in the clinic at that time. Marc was in charge of the whole process. He pretty much was the mover and the shaker of all this stuff that happened.

Hughes: How much was he actually in the clinic?

Schietinger: Well, the clinic only met on Thursdays. Every Thursday, he was there.

Hughes: There would be no reason for him to come between clinics, would there?

Schietinger: Right. Other than that, I went to his office to meet with him. So I saw him for a meeting and during the clinic, but pretty much, I worked on my own in the clinics administra-

¹ University of California, San Francisco. Ambulatory Care Center. Clinical Nurse Job Description. [Filed July 9, 1981] (Personal collection of Helen Schietinger.)

tion building. He saw patients or did the rest of what he was doing in his office.

Hughes: Was that all right with you?

Schietinger: I would have preferred to be working with colleagues. I would have preferred to have more of a working relationship with him. But you got a sense of how busy he is in your interview with him.¹ And he's always been like that. So I appreciated the time that I did have with him, and knew that it wasn't possible to have more.

It was a very isolating experience, working in such a small clinic that only met once a week. The person that I saw periodically was Don Abrams, because the oncology clinic was on the same floor as my office. But for the most part, it would have been possible for me just to not be there, and nobody would have known.

Perhaps one of the reasons the clinics administration had such an unsupportive attitude toward the KS Clinic was because they had no control over it. In fact, so much of what I was doing wasn't generating income. The clinic visits of patients were charged to the patient's insurance or to Medi-Cal, but the specimens were going to unfunded labs that were doing all of the work free. There were no patient charges generated for any of the consultations I had with the patients, or the consultations of the physicians seeing patients in the clinic.

Educational Sessions for Patients

Schietinger: Clinics administration saw the work that I was doing to develop support systems for the people who were coming to the clinic as pretty peripheral and touchy-feely and unnecessary. In fact, there was never any record of the educational sessions that I set up for patients.

Hughes: Were the educational sessions scheduled for a certain time every week?

¹ With one exception, the six interviews with Dr. Conant in the AIDS physicians oral history series were conducted in his office during his lunch hour, over soup and soda brought in by his office staff.

Schietinger: Yes, they were a regular time every week. I think I didn't start doing them until I had been there for about six months. That seemed to be the thing that people wanted the most. They wanted information; they wanted access to the physicians, to the experts; they wanted to come to the KS Study Group and hear what was really going on. And of course a theme all the way through the AIDS epidemic is the people living with HIV know more than physicians, because they keep up.

The educational sessions became a regular thing, and I expanded them to things that I thought would be useful to patients. I brought in a nutritionist to talk to them. I'd have to go through my papers and look for other topics.

Hughes: It would be interesting to know the range of subjects that you thought was worthwhile. Was scheduling a speaker a matter of hearing somehow that there was a nutritionist, for example, on the campus who might be persuaded to come and talk?

Schietinger: Yes. And having people who had come to the KS Study Group for various reasons who might have some interesting slant, or were doing some work that related, that the people who were coming to the clinic would be interested in.

Hughes: It's getting late. I think we should stop for now.

Psychosocial Services

[Interview 2: February 2, 1995] ##

Paul Dague, Shelly Hatfield, and Helen Schietinger

Hughes: I think we should start tonight with Paul Dague, whose name came up at the end of the last session. Was he one of the first psychosocial people connected with the clinic?

Schietinger: Yes, he was. He actually came in as a colleague of Marc's on a volunteer basis.¹ He was a private psychologist in the city, I believe. I don't think he had any connections to

¹ For an account of Dague's association with Conant, see the oral history with Conant in the AIDS physicians oral history series.

UC. He might have also been doing work with Operation Concern, which is a lesbian and gay therapy center that I think had some public funding of some sort.¹ But I think for the most part he was in private practice in the city.

He came in to be of support to the people in the clinic, to provide psychological services. So he and I began working collaboratively, and I talked to him about what had been going on before. I should flip through my 1983 calendar and see if I can identify when he came into the clinic.

Let me backtrack a bit, because there was a social worker at the ambulatory clinics services who made herself available to me as a consultant. Shelly Hatfield was a social worker who was able to work with me so that I had somebody to consult with. I don't think she was able to see any clients.

Hughes: Did you approach her for help?

Schietinger: She was interested in AIDS and came to the KS Study Group. I met her there and began talking to her about clients and asking her questions about resources in the city and resources within UC and that sort of thing. So we developed a relationship, and I continued to go to her office and talk to her about potential resources and things. She was very helpful, especially in providing me with emotional support. She recognized that I needed support to be doing this work. But the clinic itself, the Ambulatory Care Center at UC, did not officially make social services or social workers available at all.

Marc asked Paul to come in and consult with the individual patients who were being seen so that they would have some support. I guess he did an intake interview on each person as they came into the clinic. I think that's actually what we started doing: I would see them, and then they would see him if they wanted to.

Hughes: As I remember, you called your intake interview a psychosocial assessment.

¹ Dague was executive director of Project Concern from 1978 through 1980. He left that post to go into full-time private practice psychotherapy. (Counselor of gays dies of AIDS-linked illness. San Francisco Chronicle January 21, 1984.)

Schietinger: Yes.

Hughes: You determined what their state of mind was and what their social support system was, things like that.

Schietinger: Right.

Hughes: Wouldn't Paul have been doing something similar?

Schietinger: Well, yes. In a way, he was taking some of a load off of me. As the clinic expanded, there were more and more people coming in. What I was doing was a much broader scope. I was having to identify a lot of issues that each person had, what kind of resources they needed in terms of the psychosocial assessment, how stable they were, how they were coping. I was providing emotional support on an ongoing basis for people who were really anxious; they could call me during the day and have access to me.

Whereas I suppose seeing Paul was more like an actual therapy session, sitting down with somebody, talking about the immediate impact of this disease, and going much more in depth about his feelings. Whereas I was more doing crisis intervention, and then if someone was in crisis, trying to figure out where to go with that. But for the most part, I was assessing and then providing support, as opposed to doing therapy in a more in depth way. So he was extending the ability of somebody to deal with the illness right there in the clinic. And he continued to work with the clinic after I left.¹

Hughes: Always as a volunteer?

Schietinger: I believe so, yes. He was never paid, I don't think. Well, there were no funds. There was no way he could be paid.

Paul Dague's Illness and Death

Hughes: Paul Dague died of AIDS in 1984.²

¹ Schietinger resigned from the clinic in April 1983. (Schietinger to Conant, April 27, 1983. KSN, 1-5/83.)

² Dague died on January 20, 1984. (Counselor of gays dies of AIDS-linked illness. San Francisco Chronicle, January 21, 1984.)

Schietinger: Linda Maxey was his Shanti counselor and worked very closely with him when he was sick and dying. And that's a whole other period of his life, of course.

You know, I totally forgot this. He was seeing clients in the clinic and I was still there when he was diagnosed. I forgot that. I blocked it out. He came up to me one day and asked me to look at something behind his ear. It was a little bump, but it was definitely not a lymph node. He said, "Well, what is this?" I said, "Well, it looks like a little cyst to me. Ask Marc to look at it, but I don't think it's anything."

So I brushed it off, essentially. My response was to reassure him. He went to Marc, who did the same thing. But then Marc had him come into his office. He assumed it was a cyst, and was going to remove some fluid. But it turned out to be KS.

It was a very atypical lesion, so it wasn't just a matter of my being in denial and saying, "Oh, it couldn't be happening to Paul." But I'm sure that was there too. I don't think either one of us was able to look at the possibility that Paul Dague could have KS. He was one of the care givers. He was a gay man, which made him much more useful to the clients, because he could be there for them in a way that nobody else could. But I think being a care giver was supposed to make him invulnerable to AIDS. The possibility of a care giver getting AIDS was something that none of us had been willing to look at at this point.

Hughes: Was there an element of, if it happened to Paul, it could happen to me? Before that, was there a psychological separation between the staff and the patients?

Schietinger: The categories of care giver and patient were separate, certainly. I still thought that I was especially protected because I was a lesbian, and I was a very monogamous lesbian. I didn't have any sexual behaviors by which I could come in contact with the virus. A care giver could be exposed by sticking themselves with a needle or something, which certainly was a fear. But there was still a boundary between care taker and patient that wasn't supposed to be crossed, and it was not okay for the care giver to become a patient. It was very threatening.

Hughes: How was it handled by the staff? Because Paul continued to work in the clinic after diagnosis.¹

Schietinger: Yes, he did. Primarily, staff saw him in a well category, and therefore didn't deal with it, I think. They just put off the possibility that he would get sick, because he was fine. So that then became the separation, as opposed to, "He doesn't have KS."

I had a more intense relationship with him because, as we worked together, I talked to him about the possibility of having him be my supervisor for hours toward my MFCC license as I was doing these intake interviews. We came to an agreement that he would supervise me an hour a week. It was so that I could accumulate hours for my MFCC license, my marriage, family, and child counseling license, for which I had to accumulate experience.

But it also was a very useful situation for me to have someone to consult with about the clients that I was seeing, and therefore be able to be more effective as I was talking to them. And also to deal with my own feelings, the difficulty of working--at this point not with young dying people, but with young people who were making their own decision about what they were going to do to deal with this new disease.

For me, one of the big issues was the people who were going off and doing alternative therapies. I was concerned that they were maybe decreasing their nutritional intake because they were going on fasts. I was very concerned about a couple of people in terms of the implications of their doing the things they were doing. They weren't just doing acupuncture or something that could be done parallel to medical treatments. There were a couple of people that were on special diets, and that was making them lose weight.

I consulted with Paul about some of those issues, and he was very helpful to me in my accepting the need for control that a person with a terminal illness has, and the importance of their doing things that I might think were inappropriate. In fact, it wasn't my place to tell them so, and it might be a very empowering and important thing for them to do. So he was very useful in my struggle to accept the choices that people were making, and to learn to respect

¹ For Conant's reaction to Dague's illness, see Conant's oral history in the AIDS physicians oral history series.

the ways that people empowered themselves. So Paul was really one of the people who helped me to be effective in working with people with HIV.

Hughes: Wasn't he one of the few staff members who was consistently in the clinic?

Schietinger: Right. He was there.

Hughes: The others were coming and going.

Schietinger: Yes, that's very true.

Hughes: Was there anybody else that was around when you were around?

Clinic Routine

Schietinger: The Thursday morning crew became regular. And there were a number of community physicians who came in and donated their time. There was an internist who came from Daly City, [Arthur Halliday], a very wonderful physician who did a complete history on every person. Marc recruited him to come in to do physicals systematically so that everybody got a full physical when they came to the clinic, and then Marc would do the dermatological exam.

A year had transpired since my arrival by the end of 1982. The clinic was very systematic by this time. This group of physicians would come in, and they would be there for clinic from eight Thursday morning until I think it was about one o'clock, when the KS Study Group convened. There was a certain number of slots for patients on Thursday morning, and I would fill those, and then I wouldn't accept any more clients for that clinic day.

Then the KS Study Group happened when clinic was over. The patients came, got what they got, and had to leave. Then we were all focused on this forum, where there would be a presentation and scholarly discussion about what was going on and the newest findings about AIDS.

I can't remember what Paul did. He must have come in during that time and seen people. I think we found a room somewhere else, separate from the clinic, that he could bring people to. Maybe he went in my office. But he was able to sit and talk to an individual for perhaps an hour.

I always had people come in a day or two before clinic, because there was no way that I could coordinate everything that was happening and keep things going, and also actually sit down and talk to people. I needed an hour and a half with each person. Well, I didn't at first, but then they wanted to sit and talk. They wanted the time. They wanted to be able to ask questions, and they needed to know what to anticipate. So I gave myself that hour and a half by having people come in before their appointment in the clinic.

Other regular people coming to the clinic: Steve Mehalco, who was a general practitioner. He was a gay physician who had, I believe, a private practice, but he came in and donated time. He and Arthur Halliday are the only ones I remember as being regular physician volunteers. Then there were the people that always came to the study group. It was always a delight to see the folks and talk about things together. But it was a very small group of regular people. Paul Volberding and Donald Abrams were there, of course.

Hughes: So Paul and Marc and Donald and Steve and Arthur were the physicians always there on clinic days?

Schietinger: On the clinic morning, yes.

Hughes: But not in between? You said that Abrams was sometimes around between clinics.

Schietinger: Well, he was seeing lymphadenopathy patients in the oncology clinic.¹ So he was still not focused on the KS Clinic at all. There really was no clinic except on Thursday mornings. Then in between there was me doing the follow-up and the follow-through and the coordination or the scheduling--there was a lot of scheduling of things that needed to happen at other non-clinic times.

Handling Biopsies

Schietinger: To schedule someone for a lymph node biopsy would mean making that appointment at the clinic where they would be biopsied, making sure that I could get the dry ice, be there

¹ See the oral history with Abrams in the AIDS physicians oral history series.

when the physician was doing the lymph node biopsy, and then take the biopsy specimen. I was always very concerned about the emotional well-being of the people who were going through these processes. They usually were afraid; they were afraid of what was happening to them, and they were afraid of what they were going to find out.

So I felt it was useful for someone that wasn't a stranger to be there when a patient came for one of these procedures. Then I would have to take the specimen and go over to the pathology lab, and have one of the people in the pathology lab section the specimen so that parts of it could be frozen and taken to a particular lab, and some of it could be taken in saline over to somebody else's lab, and something sent over to Larry Drew's lab at Mt. Zion Hospital. So there was a lot of coordinating and a lot of keeping track of the requests of the various people who were doing some of the initial--I wouldn't say research, but fishing expeditions--to find out what was going on with this new disease. So there was a lot of accommodating that I had to do.

I remember once bringing a biopsy specimen over and having it sliced, and I was very aware that the pathology lab is the dirtiest place in the hospital. It is a nasty, filthy place where there are these parts of bodies that are being thrown around. There's nothing sterile about it. But I needed to keep this specimen sterile because it was important to see what was growing in the lymph node. So it had to be cut by the pathologist for some reason, but it had to be sterile, and their environment was not sterile. So I had to bring over all the sterile equipment and supervise them to make sure that they didn't break sterile techniques, so that whatever I sent over to Larry Drew wouldn't be contaminated.

While I was waiting for a pathologist to come around and be ready to do this, I noticed that the poor lymph node was drying out. I went over to Jay Levy's lab--he wasn't there, but somebody else was--and I asked for some sterile saline and opened the top to the jar that the specimen was in. They knew that it was a lymph node from a person with Kaposi's sarcoma. I remember them yelling, "Don't open that! Don't open that!" These people, whom I considered the insiders who wouldn't be afraid, were very afraid of the virus popping out and flying through the air. But they knew something that I didn't know. They worked with biohazards under stringent laboratory conditions, and I suppose associated AIDS with viruses such as Ebola. They were

trying to isolate an unknown infectious agent, and had a healthy respect for what they didn't know.

Attitudes towards and of the KS Group

Hughes: How did outsiders see this group and what it was doing?

Schietinger: Was it on tape that I described the clinic administration's attitude toward me?

Hughes: Yes.

Schietinger: So there was the attitude that this clinic was a waste of staff time. Outsiders lacked the perception that this epidemic was a very significant thing that was happening.

There was the handful of scientists--people like Art Ammann and Conrad Casavant and the folks who were involved in research as a part of their clinical practice, or in pure research in some cases--who were very concerned and interested from a scientific point of view. As I said, the disease was a big mystery. It was a big epidemiological mystery to be solved. So there was something fascinating about it.

My impression of most of the people who were initially working on the disease from that end of things--Larry Drew and the people that were the most involved in donating the resources of their labs, as opposed to the disinterested people that wouldn't donate any resources and didn't care--were concerned both on an intellectual level and on a personal level. I think there was an awareness that this epidemic was very, very serious. The fact that it was a sexually transmitted disease that was killing people, and was probably caused by a virus, and therefore was not going to have an easy cure, was there in those people's minds.

I know that Jay Levy was very concerned about the issue of how the agent was transmitted. They had special biohazard hoods in their lab and were working with very dangerous viruses. They knew back then about the things that Laurie Garrett just wrote about in her book, The Coming

Plague,¹ which is fascinating. I didn't have any idea back then.

Most of the people that were there in the very beginning of the epidemic have continued to be involved. They were involved before there was money, and then the rest of the world got involved when there was money.

Motives for Involvement in the Epidemic

Schietinger: In June 1982, I went to Houston to the Lesbian and Gay Health Conference, which had met for a number of years. But there was in 1982 a forum, a panel of experts to talk about this new disease. I had come from the KS Clinic; Jim Curran had come from the CDC; and then there were some physicians from M.D. Anderson Cancer Center.

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Schietinger: Before the panel began, we stood around and introduced ourselves. Some of the physicians were talking at that time about their tickets to Stockholm. I really did not make a connection until the International AIDS Conference was actually convened in Stockholm [1988], and I realized that the Nobel Prize is given in Stockholm and that these physicians were very interested as researchers in the possibility of getting the Nobel Prize by discovering whatever this virus was, or doing whatever would cure AIDS, or whatever.

The conference in Houston was held when the acronym AIDS had just been invented. Or maybe it hadn't even been invented at that point, because the workshop was about Kaposi's sarcoma.

Hughes: It was the summer of 1982, when the CDC--

Schietinger: Finally made that official.²

¹ Laurie Garrett. The Coming Plague: Newly Emerging Diseases in a World Out of Balance. New York: Farrar, Straus and Giroux, 1994.

² Official use of the acronym, AIDS, began in the summer of 1982 and expanded rapidly after the CDC began to use the term in its reports. Who coined the term is a subject of debate. See: Mirko Grmek. History of AIDS: Emergence and Origin of a Modern Epidemic. Princeton, N.J.: Princeton University Press, 1990, p.32.

I think there were some opportunists early on who saw this disease as an opportunity to become rich and famous. But for the most part, before there was research money available, the people who were involved were in it because they were concerned. Then, of course, there were the people who were already connected to the gay men's community, and the health providers providing services to the people who got sick, wherever they were coming from, who were very touched and concerned on a personal level. And then I think all the researchers became personally touched as they worked with people with the illness.

Specimen Collection and Banking

Hughes: You talked about the importance of collecting specimens. As early as 1982, specimens were beginning to be banked, I think on a rather erratic basis.¹ There was no funding for the bank yet.

Schietinger: That's true. Specimen banking was irregular and informal.

Hughes: Were parts of every specimen saved for the bank?

Schietinger: Not unless somebody was there to grab it. If I wasn't there to say, "This is not just a specimen to be looked at for the pathology of it," then I think a piece of it would go over to Dick Sagebiel's lab and he would do the pathology reading. And I guess the rest of it would just be thrown away. Certainly the university was not saving anything. Maybe Dr. Sagebiel was saving some; he might have been concerned about being able to go back and look at specimens later.

Hughes: I think it was the appropriation from the state of California in 1983 which provided the first money for an AIDS specimen bank at UCSF.

Schietinger: Interesting.

¹ According to John S. Greenspan, B.D.S., Ph.D, the AIDS specimen bank at UCSF received its first specimen on November 16, 1982. (Personal communication from JSG, summer 1994, after referring to specimen bank records.) For more on the bank, see the oral history with Greenspan in the AIDS physicians oral history series.

Hughes: But that money may have come after you had left the clinic. Is that the case?

Schietinger: I think it did. John Greenspan was already making some space available in his freezers for AIDS specimens, but it was all donated.

Informed Consent and Confidentiality

Schietinger: There was no system for labeling specimens, and early on, there was no awareness within the clinic that there was any need for informed consent for specimens to be saved, or any concern about confidentiality or anonymity or unlinking of the specimens from the name of the person from whom they came.

I don't think the need for confidentiality occurred to anybody. It didn't occur to me until I found out that the CDC was very concerned. When I collected blood for the CDC, people signed a consent form that I sent with the blood. I don't remember if I just numbered the specimens with some numbering system, or if I put the name on them. But the CDC kept all of their data in a locked file cabinet in the basement offices at CDC in Atlanta. The CDC had a big file cabinet that had this huge iron thing on it with a huge padlock that was locked, and then the room was locked. They were extremely conscious from the very beginning of the importance of protecting the confidentiality of anybody whom they were working with.

Hughes: Where did that concern stem from?

Schietinger: I think they were mostly people who had worked in the field of STDs [sexually transmitted diseases]. The field of STDs already had a very careful legal system set up to protect people, because it was acknowledged from the beginning that people would not come for STD treatment unless their confidentiality was protected. So in order to gain the trust of the public that they were trying to protect, the CDC needed to take very careful measures to make sure that the names of the people who came to the clinic wouldn't be in the paper the next day. That sort of thing.

I was more concerned with confidentiality of patient charts, knowing that in the gay community people are worried about going to a gay bar and then getting arrested by the

police and having their name in the paper the next day. There's a very real fear of the stigma of being homosexual. But somehow, the laboratories to me were off limits, out of the real world, so that wasn't a part of it that I thought about.

Hughes: Apparently, nobody else did either.

Schietinger: Right. So it wasn't until later that careful, systematized, unlinked data collections happened.

Hughes: Later, meaning after you left the clinic in spring 1983?

Schietinger: Yes, I think so. I don't think we ever did set up anything that was unlinked. It came with the funding. It came with then having to be approved by the human subjects committee [UCSF Committee on Human Research], whereas before, it was an extremely informal process of data gathering that wasn't really considered research.

Hughes: And didn't involve federal money.

Schietinger: Right, that's true. Although I would imagine that the American Cancer Society would have expected, if there was research going on, that there would be protections and an approval by the human subjects committee, et cetera.

So I feel good that I went through a process of connecting with the human subjects committee and getting an informed consent and a protocol developed, but it still was a pretty informal process, and didn't cover things in the way that later became very formalized, as formal research happened.

Hughes: Do you think that the epidemic itself had any influence on IRBs [Institutional Review Boards] and consent forms and the paraphernalia associated with obtaining patient consent? Because of the need to maintain patient confidentiality, did the regulations become more stringent, or were they already?

Schietinger: For research, they already were. I think that within the world of research, most people were aware, or had to be made aware, of the requirements of human subjects committees (such as where they were going to keep their files). They were asked those questions as they submitted their research protocols to the human subjects committee for approval.

Infection Control

Schietinger: The place that it did have an impact was in patient care, on the level of labeling specimens going to the lab. Early, all the specimens from people with AIDS were labeled in some way. I can't remember; I think it was something like, "AIDS/Hepatitis B precautions," or something like that.¹ That was what was put on the front of the chart that was put on the patient's door, and that was put on all the specimens that went to the lab.

And then there was very quickly an awareness that that was a horrendous stigma to put on somebody, and then the labelling was changed. This awareness happened hospital to hospital; you would say just, "Blood precautions." It was actually the infection control practitioners who argued with the care providers and the policy makers that nothing different was supposed to be done with these specimens. That you never were supposed to touch the contents of a specimen jar anyway, and you should never do certain things.

Hughes: Regardless of whether or not the specimen came from a person with AIDS?

Schietinger: Right. So the concept of universal precautions did get developed. Grace Lusby was very important in my understanding of the whole rationale for not stigmatizing somebody by labeling things from them.

Hughes: There was no need to if universal precautions were observed.

Schietinger: Absolutely no need.

And the fight over that was tremendous. It was very difficult. When I went a number of years later [1986-1988] to the California Nurses' Association to be in charge of a program to train health providers about AIDS [CNA Train the Trainer Program], we taught people all over the state about universal precautions. The rank and file of the California Nurses' Association was calling up the office and the

¹ In a memo to "Laboratories Handling Specimens from Kaposi's Sarcoma Patients" and dated October 19, 1982, Schietinger stated: "We will label all specimens submitted to the lab 'Kaposi's Sarcoma.' For blood specimens, this means they should be handled in the same way that blood from a hepatitis B patient would be handled. For urine, feces, etc., the same applies." (KSN, 3-12/82)

California legislature saying, "Those people up there at CNA don't represent us. We don't want universal precautions. We want our patients tested and labeled." [laughs] And it was very difficult to reach people who were really afraid and to change their conception of what it was they were protecting themselves from and how they needed to protect themselves.

Treatment for Kaposi's Sarcoma and Opportunistic Infections

Hughes: Talk about treatment in the early days. What did you do once a person was diagnosed with KS?

Schietinger: If they had fairly advanced KS, they were referred up to the oncology clinic, where they would be treated with chemotherapy. There was one young man who had huge lymph nodes. His whole neck was visibly swollen with Kaposi's sarcoma. The chemotherapy quite effectively reduced the lymph nodes and rendered him very able to function and continue living his life for quite some time. So if the KS was advanced, there was something to do about it.

I really am going to have to go look in my files and give you the thing that I wrote out to give to people. We started talking about the importance of nutrition and reduction of stress and doing things to take care of yourself--trying to stop smoking, and that sort of thing. Take aspirin if you have a fever, make sure you have plenty of liquids, not to feel bad about sleeping, to rest as much as you need. And really, that was about all we had.

We didn't have acyclovir. It was an experimental drug. They didn't know if they trusted it or not at that point. I think that they were just starting to use acyclovir topically, but there was no internal acyclovir, it seems to me. I may be totally wrong about this, but it seems to me that acyclovir had not been approved yet when the epidemic started. Certainly when someone had a really bad herpes infection, prescribing acyclovir was not something that was just automatic. I don't think it was used.

Hughes: How did you handle opportunistic infections? Were they referred to the infectious disease specialists?

Schietinger: Yes. Usually people wouldn't come to the clinic with an opportunistic infection. They would have gone in an acute illness to an emergency room or to their physician. I know that a number of people were treated inappropriately with antibiotics when they came in to an E.R. with some nonspecific kind of pneumonia, sent home, would come back worse, would be put on another antibiotic, be sent home, and then they would come in extremely hypoxic and have to go immediately into ICU and be put on a respirator because they had gone into respiratory failure. At which point they would be diagnosed with *Pneumocystis pneumonia*.

As time went on, the people who came to the right doctors would be worked up appropriately and expeditiously and treated quickly. Or if they already had KS, they would be followed very closely by someone who would suspect *Pneumocystis pneumonia*. Actually, one of the things we were doing in the KS Clinic was to do baseline pulmonary function tests. (I guess that was another thing that I had to schedule for them.) The staging that people went through was to get a baseline of what their overall functioning was. So I would schedule them to go to the pulmonary function lab, and they would go through a number of exhausting tests.

Hughes: Which were aimed at deciding whether indeed they did have *Pneumocystis*?

Schietinger: No, this was for asymptomatic people: What is the status of your lungs at this point? Then they were able to identify abnormalities in the pulmonary function studies that were early signs that this person was coming down with *Pneumocystis pneumonia*. Which is very, very difficult to diagnose. It can have a very slow onset, an insidious onset, that doesn't look like anything. It's subclinical. But they actually were able to identify some particular patterns of respiratory dysfunction that were associated with the beginnings of a *Pneumocystis* infection.

So a lot of that baseline stuff helped the pulmonologists to begin to make some conclusions and to know how to work people up. At that point, if someone was diagnosed, they would have admitted them to the hospital and treated them for the *Pneumocystis pneumonia*. Depending on the hospital they were in, they would go into respiratory isolation for fear that it was infectious through the air. Nobody knew enough about *Pneumocystis pneumonia* in adults to know whether it was or not.

After I went to the Shanti Project and was working with people living with AIDS in the community and having contact with people in their everyday lives, it became clear to me how little I had known about the people who came to the KS Clinic. Before working at the KS Clinic, I had done a lot of home care, and I have made a lot of home visits in my profession as a nurse. It's a very, very different situation to visit someone in their own environment, where you have a lot more cues as to what's going on or what's not going on, than when somebody walks into a clinic with all their defenses up and wanting you to think that everything's fine.

One of the things I feel that we probably didn't pick up in the clinic setting was what later came to be called HIV dementia, AIDS dementia. I began to be very sensitive to the subtle signs of it when I was visiting people in the residences and seeing people as they were functioning and interacting, and talking to people's roommates who were beginning to be worried about them. But we didn't know anything at the beginning to be suspicious of. So it was not until someone began to have signs of a stroke that it would be diagnosed as toxoplasmosis. They would be in pretty acute stages of the infections before anybody diagnosed them.

So one of the things that has been a tremendous advance, through experience with the natural history of the disease, is that things are picked up earlier. It's not just that we have the treatments, it's also that they're picked up earlier, or that people are put onto prophylaxis so that they don't come down with them. Those things just make a tremendous difference. It's so exciting that those things have actually become the standard of practice, and none of it was there in the early years.

Patient Referrals within the Hospital

Hughes: Clarify the picture that I am developing of patients coming in with a variety of symptoms, and consequently going to different places in the hospital. You mentioned the emergency room. They of course could be referred to the KS Clinic. Supposedly if their primary problem was an opportunistic disease, they were referred to an infectious disease specialist.

Schietinger: Or a gastroenterologist.

Hughes: Was it the referring physician's task to figure out where best to send his patient?

Schietinger: Well, in the KS Clinic we didn't ask very many questions about insurance. That got taken care of with the billing folks. They were billed--their insurance was, or whatever--for a visit to the dermatology clinic. When the clinic physicians decided they wanted to do a particular work-up, they didn't refer back to the referring physician, I don't believe. Finally, Marc actually did develop a systematic way of dictating his notes, but also dictating letters to the physician describing what was going on. I think it took at least a year before there was that protocol and that relationship developed with the referring physician.

I think the pulmonary function studies were all free. They couldn't be justified medically. Most of the tests, like the lymph node biopsies, were medically justified. If the person had been referred to UC, they went to UC for the tests, not back to their existing hospital.

Hughes: If a patient had multiple symptoms--KS and an opportunistic infection, maybe even lymph nodes--where did he go first?

Schietinger: When they came to the KS Clinic, that was their central place, unless they needed chemotherapy, in which case they were referred to the oncology clinic. If they were referred for tests or a consult, a GI [gastrointestinal] consult, the results would be reported back to their medical record, which then we would make sure came to the KS Clinic with them. So I suppose that initially what became the group of physicians that met regularly in the KS Clinic was essentially the group of experts seeing AIDS patients in San Francisco.

Hughes: That's understandable, as long as the patient had KS. What if a patient came in with just *Pneumocystis*? What would happen to him? He wouldn't come to the KS Clinic.

Schietinger: He wouldn't come to the KS Clinic. He would go to his regular physician, and there were people like that all over the city, in various doctor's offices and hospitals. There were a number of times when there was somebody (a researcher) who would want to do a series of lymph node sections to look at a bunch of things, so I would send a specimen from the next five lymph node biopsies to that person. There were some times when someone wanted a lot of

blood specimens from a lot of people, and I would be referred over to a patient at San Francisco General, or to Kaiser, or to the VA Hospital, to draw blood and bring it back.

Hughes: For the researcher?

Schietinger: For the researcher, yes. This was mostly a research clinic, and essentially it never became a place for patient-centered care.

Hughes: It was a research clinic that was structured around KS.

Schietinger: Right. .

Hughes: That was why the patient was there. If he had other problems, he was referred from there.

Schietinger: Right. But they were also looking at pulmonary functions, they were looking at--well, for the GI studies, the sigmoidoscopies had to do with looking for KS in the GI tract. Because this KS Clinic was where there was a group of patients, as opposed to individuals in various private physicians' offices, this was a place to systematically access patients with the strange new disease.

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Schietinger: For example, Art Ammann was testing a theory. He really was looking at the immune system, and he wanted to know about the function of the cellular immune system. So we were recruiting a certain number of people to be immunized against a common infection--actually, I don't remember what it was. Then we were doing a series of skin tests and looking at the ability of the immune system to respond, at whether there was a skin reaction or whether the person was "anergic," and then drawing blood to see what the T cells were doing. That didn't really have anything to do with the KS. But there were enough people coming to the clinic to be studied that those kinds of studies could be done with them.

But if people needed medical care, for the most part, they had to go back to their own doctors.

Hughes: Don Abrams' lymphadenopathy patients weren't necessarily presenting with KS, were they?

Schietinger: No. They would go to the oncology clinic. So there was another place that people were being referred if their symptoms fit the criteria.

Hughes: How was he getting those patients to begin with?

Schietinger: The same way that Marc got patients to come to the KS Clinic. He got physicians to refer people to him. He got physicians to be suspicious that lesions were something to be concerned about, through meeting with community physicians. Well, there actually already was an organization. The Association of Physicians for Human Rights was a lesbian-gay physicians' association which had a local chapter in San Francisco [Bay Area Physicians for Human Rights]. So there was already a network of professionals that could be accessed through an association. But also I think just word of mouth, periodic rounds at the various hospitals perhaps. It was pretty informal that way, I think.

Defining A Case of AIDS

Hughes: How early was it clear that all these different conditions were aspects of one multifaceted disease?

Schietinger: It already was clear when I came aboard, at the first KS Study Group that I came to in 1981. That was already the conclusion. The list of people with this new disease wasn't just the people at the KS Clinic. The list was a list of names, and the hospital they were admitted to, and whether they were still alive or not. And there were a number of different diagnoses on that list.

The central fact in San Francisco was being a gay man with an unexplained illness that didn't get better with treatment, and therefore bizarre infections were looked for. That was the key. The known quantity was being a gay man. I'm sure it was more problematic in New York, with injecting drug users getting AIDS.

Hughes: I can't remember when the CDC first mentions risk groups, or whether that first definition is aimed just at gay men.

The Role of Epidemiology

Schietinger: Oh, the definition has nothing about risk groups in it, and it never has. It's brilliant. You know, epidemiologists are pretty smart people. I have a real deep respect for them. I'm really impressed at what they came up with so early. Because the CDC definition applied to anybody with an illness that happens only in people with an immune deficiency, but with no other reason for that immune deficiency. (And then they list reasons for having an immune deficiency, such as treatment for cancer.)

The definition included an age limit, so anybody over sixty-five doesn't fit because your immune system deteriorates after sixty-five. And then they list specific diseases associated with AIDS. But they also at that point kept open the possibility that they would find other opportunistic diseases.

Hughes: Are you thinking mainly of the CDC epidemiologists, or are you also thinking of the local epidemiologists?

Schietinger: I tend to think of the CDC epidemiologists, the ones that went to New York and did the case-control study, the ones that actually put two and two together about the injecting drug users and were suspicious that something was going on. Although I'm sure that Selma Dritz was part of that at the very beginning, but I have a feeling that the CDC epidemiologists were really the first ones to look at it, except for the clinicians, and those weren't epidemiologists. The clinicians were saying, "There's something going on here, because in my patients, this is happening." And that was how they identified that they were all gay men. "Well, now we've got some Haitians." "So, why are these Haitians included in the risk groups for AIDS? There's no reason for them." That never did fit.

Hughes: You mentioned the locked cabinet where the CDC kept its specimens.

Schietinger: Well, its records. Its specimens weren't kept in locked cabinets. I already said they had to not have names on labels. I had to not send names to the CDC. I think I sent numbers. They sent me the labels to put on, with numbers on them.

Hughes: Did the CDC epidemiologists occasionally come to the KS Clinic?

Schietinger: I don't remember them coming to the clinic, but I'm sure they did. When they came to the city, I would think they would have wanted to see some patients. They certainly came and spoke at the KS Study Group.

Hughes: But you don't have memories of those now-famous people?

Schietinger: Right. I remember sitting down and having long talks with Andrew Moss, Michael Gorman, and some other local epidemiologists, and Bill Darrow, and Harold Jaffe and Jim Curran from CDC. But I don't remember them in the clinic.

Hughes: Speaking of Andrew Moss, do you remember that in the spring of 1983, there was a furor over the census track data that he was collecting, and his discovery of the high incidence of AIDS in the Castro District of San Francisco, and whether to release the data or not?¹ Do you remember discussions?

Schietinger: I don't remember discussions. I know that that was an issue.

AIDS Education

Debate over Approach

Schietinger: That summer there was also an issue about how to go about doing education, whether to use scare tactics or to use health education principles in which you give people achievable goals with increments so that they don't feel as if it's hopeless, and they'll never be able to change. That discussion was also happening at the same time.

Hughes: In the clinic, or just in general?

Schietinger: In general. At the Denver conference. After I went to speak at the Houston Lesbian and Gay Health Conference [1982], that conference happened the next year [1983] in Denver. Attached to it was an AIDS forum. It was the second AIDS forum; the first one had been the one that I spoke at. I was a chairperson for the second one in Denver. All of those issues were dealt with and thrown around and

¹ See Moss's oral history in the AIDS physicians series.

struggled with among primarily lesbian and gay clinicians at that conference, and also activists from New York and from San Francisco and other places.

Hughes: With any resolution?

Schietinger: Well, there was some resolution, but the biggest problem was that the epidemiologists couldn't guarantee safe sex. They couldn't say, "This will absolutely for sure protect you against AIDS." The gay community wanted guarantees, wanted to be told: "You can do this; you can't do that," and nobody was going to do that. The only thing that the clinicians were willing to do was to say, "These are the things we know. These are the things that may protect you, and this is what you have to choose from. Here's your menu. Now, you make your informed choice once you educate yourself. Decide how much of a risk you're willing to take, how much of a risk is worth it to you." So that underlying problem got in the way of a lot of things.

Steve Morin, who now is working with Congresswoman Nancy Pelosi and has been working very closely on the Hill with AIDS legislation, was one of the people we invited to be a co-chair for a workshop that was called, "Changing Sexual Mores among Gay Men," or some awful title. He was a gay psychologist who was working in the gay community, and I've forgotten who his co-chair was.

What we had wanted to do was bring together people from the media, from the pornography industry, essentially to talk about ways of eroticizing safe sex. But that conversation couldn't happen, because the community was still obsessed about whether or not using a condom was absolutely safe. If the doctors weren't going to tell them that, and the epidemiologists weren't going to say, "We guarantee that if you use a condom, you will not get AIDS," then nothing could move beyond that.

Hughes: How frustrating.

Schietinger: Yes, it was very frustrating.

Bobbi Campbell's Brochure

Schietinger: In the meantime, some of the first activism had already happened. As I said, Bobbi Campbell had put posters up of

pictures of his lesions, but he was also one of the Sisters of Perpetual Indulgence doing street theater. They had put out--and I don't have a copy of it--the first safe sex brochure related to AIDS. They put out a brochure with cartoons, and it was just wonderful. It was a fantastic little brochure. I'm sure I have it somewhere in my files, but I couldn't find it when I was looking for things.

Hughes: That was how early?

Schietinger: It was certainly early 1983 for sure. Could have been late 1982. But it was informal.

Hughes: Was that one of the first educational efforts?

Schietinger: That was the first educational effort in SF.

Hughes: So it took quite awhile, didn't it?

Schietinger: Yes.

Hughes: Was that a question of numbers of AIDS cases before people realized that the disease really was a public menace, that you'd better warn people?

Schietinger: No. I think there were a number of things going on. There were different organizations involved in different parts of it. The health department was a cumbersome place. There was the Office of Lesbian and Gay Health, which was working with the epidemiologists to give correct information and to figure out ways of educating that wouldn't scare people.

There were the BAR [Bay Area Reporter] and the other gay newspapers which were perfectly happy to have sensational stories about AIDS in the front of their paper. But they certainly did not want to have any decrease in the ads that were bought by men that were selling sex, the bathhouses that were selling sex, the bars that were selling sex. That was the major place gay newspapers got their money. So there really was a schizophrenia in all the newspapers--well, no, Coming Up was different. But the San Francisco Sentinel and the BAR were sort of schizophrenic in their desire to support and to be worried about the AIDS epidemic as news, but to separate that from their source of income. And that was true in the bathhouses.

Hughes: The gay community was also protective of the civil rights it had won.

Schietinger: Absolutely. That's very true.

Hughes: So I imagine there was schizophrenia there, too.

The Bathhouses

Hughes: How do protection of gay rights and the health and welfare of the gay community relate?

Schietinger: Right, the bathhouse issue. The arguments centered around whether or not the bathhouses are a good place to educate people. Keep them coming and educate them was one argument. Other arguments: Close the bathhouses; this is where people are having all the sex, and, Don't close the bathhouses, because this is a hard-earned right. If you close the bathhouses, they're going to close the bars, and they're going to use this as an excuse to get all gay people off the streets, et cetera.

So yes, all of that was going on. There were various positions taken by the different political clubs. There were a lot of factions that I didn't connect with because I wasn't part of the political scene that was happening.

Hughes: Did you nonetheless feel the tension at times, because in a way, you were wearing two hats.

Schietinger: Right, I was absolutely.

Hughes: You are a member of the gay community, and you made that very clear. You're also a health provider. And those two roles were sometimes in conflict, were they not?

Schietinger: They were in conflict. There was a part of me that was very concerned about the welfare of gay men who needed their self-esteem and to be validated for being gay, and the part that acknowledged that this disease is sexually transmissible.

A Study of Long-term Partners

Schietinger: I'm going to shift gears a little, but maybe we can come back to it. One of the things that we started to do before I left the clinic was to do a prospective study of the long-

term partners of the people in the clinic. This was another one of those things that was done with no protocol, no formal connection to the human subjects committee. We invited the lovers of people coming to the clinic to go through a process of getting the baseline studies done, and getting lots of blood work, and a full physical, and a work-up, and to be followed to see if indeed they got sick, or to try and find out what was different about them, and why they weren't sick, if their lovers were sick.

I felt very satisfied in my own mind that there had to be something different about these two people, if one of them had gotten this disease and one hadn't. Clearly, this one must be immune to the disease, and therefore I was very reassuring to people who were the partners of people who were infected, that they were okay. One of the parts of my denial, was, "Okay, it is sexually transmissible. It's important for everybody out there who is sexually active in the gay men's community to start wearing condoms, but what do you do with these two people who are partners and who are lovers?"

I think essentially we counseled them that it would be a good idea for them to use condoms because of the possibility that there is a cofactor, and that continuing to be exposed to the virus was probably a bad thing. So there was advice being given to people. I think my advice differed from Marc's advice, as we went through time. He became more and more adamant that abstinence was really the only way to be sure, that you really should not have anal intercourse, essentially. That was the main thing he was saying.

Hughes: Even with your long-term partner?

Schietinger: Right, even with your long-term partner. I was saying, "We don't know, but it's up to you. This is what we see so far. One of you is relatively healthy, so make your own decisions."

Hughes: Well, I can see how two partners being told, "I'm sorry, but you just must not have intercourse at all," might say, "To hell with it." So maybe to avoid that response was part of your motivation?

Schietinger: Right.

Hughes: Don Abrams hoped that gay lymph node syndrome was not prognostic for AIDS.

- Schietinger: Yes, that it was prognostic for defense against AIDS, that these lymph nodes meant that your immune system was fighting the disease, and so that was good. I remember discussions where that was the theoretical positive outcome that might be true.
- Hughes: There was no reason not to think at that stage that that might be a possible outcome. Now that we know that it's not true, it's easy to look back and say, "Well, I was in denial."
- Schietinger: Yes, right.

The Clinic's Physical Layout and Functions

- Hughes: What was the physical layout of the clinic?
- Schietinger: Well, the clinic itself has a reception area, and there are chairs around for people to sit in in the waiting room.
- Hughes: The clinic is used for many purposes?
- Schietinger: It is used for dermatology, five days of the week, except on Thursday morning when it became the KS Clinic. We only had a limited time, because the clinic then would turn into a dermatology clinic in the afternoon, so we had to get out. Sharing the clinic space became less and less of a positive situation as time went on. But when I first started working there, we had full cooperation from the head nurse, the nurse who ran the clinic, and the staff did all of the billing, and whoever they could get insurance from, they did. I think we were assigned two rooms that we could use in the clinic.

A corridor that was an L-shape went from the waiting room, so that there were rooms along that hall, and then there was a right-hand turn, and more examination rooms as you went down the hall. At the end was the classroom, the large conference room that we used for the KS Study Group. My office was on the same floor for the first year, but way around the corner, so that I pretty much packed up my stuff and came around to the clinic when we had clinic.

I think I had assistance from a couple of the clinic assistants. There were a couple of clinic assistants who brought people into the examination rooms, and put the chart

on the door, so the doctors could always move right on to the next patient. The KS Clinic went very differently than the dermatology clinic: we assigned one exam room to each doctor and moved the patient from room to room, as opposed to putting a patient in the room, and then having the doctor come to see him. Ultimately, we made the KS Clinic into an assembly line with each doctor being a station that the person moved to. It was a very fast-paced.

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Schietinger: Marc thinks fast. The man is brilliant. His mind is going all the time. He's hard to keep up with. And the same with everybody else. I mean, there was not an easygoing pace--well, that's not true, because both Marc and Paul, and certainly Don, did take time to answer patients' questions. When they were one-to-one with a patient, they were there with the person.

I always encouraged people to write down their questions. I've always told patients, "Make your list. Make sure the doctor sees the list so he knows that you've got four items on it, so he doesn't stop and dismiss you after the first question." I tried to structure it so that the patient could actually have that consultation with a physician that means so much to the patient. Sometimes it would happen, sometimes it wouldn't happen. But it was a very fast-paced, frenetic morning.

Hughes: And the patients probably felt that?

Schietinger: A lot of times they did. I think I felt it a lot more than they did, in my need to make sure that things kept going, and that people moved on quickly so that we could see everybody who needed to be seen.

Hughes: Did people keep their tempers?

Schietinger: Yes. I think so.

Hughes: There were no scenes.

Schietinger: No. There were no scenes. There were times when somebody wouldn't show up--

Hughes: A physician, you mean?

Schietinger: Yes, there were times when Marc would come over late, so clinic couldn't start. Or Paul would get stuck at San

Francisco General and not show up. We could not extend the hours of the clinic. It was not negotiable. The clinic's administration begrudged us additional rooms when we asked for them. It was not a friendly environment to be in. I personally had nice relationships with the reception people, and we were on friendly terms, but that doesn't help when the entire KS Clinic is considered a sore thumb.

Fear of Infection

Schietinger: As there was more awareness of the infectious nature of this disease, more anxiety developed in the dermatology clinic. Then suddenly there were red plastic bags in all our garbage cans on the morning of the KS Clinic, and every bit of our garbage had to go into the red bags and be tied and thrown away, even though most of what was being disposed of was just regular garbage. All of it was not supposed to be touched anyway. Remember, this was supposed to be universal precautions! But it didn't help. So their clinic staff's anxiety was very difficult to allay, and their overreactions to the KS Clinic's existence were difficult to put up with.

Hughes: Was there fear of the patients themselves?

Schietinger: I don't remember any staff wearing masks. That would be the true sign, if staff were wearing masks around the patients. But there was also a real valid reason for there to be anxiety. One of the residents who was doing a biopsy sliced her finger very seriously with a scalpel. That was one of the first serious exposures to the blood of an HIV-infected person, and it was very frightening for everybody. It was very frightening. There was no HIV test, for one.

Hughes: Do you remember when that was?

Schietinger: No, I don't. It was sometime during the eighteen months when I was nurse-coordinator [laughter]. We can narrow it down to these months [January 1, 1982 to late spring 1983].

Hughes: The years before discovery of the virus.¹

Schietinger: Absolutely.

¹ Isolation of the AIDS virus, only later to be named HIV, was officially announced in April, 1984.

Community Services

The Shanti Project

Hughes: Have we said enough about the community volunteer system?

Schietinger: Early, there was no community volunteer system.

There were two things that did start happening early. One was with the health department's Office of Lesbian and Gay Health. But in terms of volunteer services: the Shanti Project was a little organization in Berkeley that was about to go under. It was a little agency that was not a hospice agency; it was an agency that trained volunteers to do bereavement counseling. Volunteers would meet with people who were losing a loved one, or who had lost a loved one, and help people go through the process of loss surrounding death.

Their board tried to dissolve the organization, and the volunteers decided they didn't want the organization to fold, so they took over and became the board members. One of the volunteers was Jim Geary. I don't remember ever meeting him back then, but he had the first support group for gay men with this strange disease. I don't know how it got together, but there was a small group of men with Kaposi's sarcoma who met together.

Shanti resuscitated itself to provide volunteer services to people with AIDS. As the volunteers became the board members, they reshaped the organization to do that. Jim I think had been a ward clerk or ward attendant, and quit and went on unemployment. While collecting unemployment, he worked as the director of Shanti as they first got started in San Francisco. They recruited some volunteers, did a training, and made themselves available to patients.

So after a few months of my being at the KS Clinic, there was this resource that I could refer people to. I could say, "There's the Shanti Project." It was very important at that point to have that resource, and I think the most important part about it was the support group where people could meet each other.

Hughes: Shanti, unlike their presence on 5B [the inpatient AIDS ward at SFGH], was not physically in the KS Clinic?

Schietinger: No. There was never any contact with that clinic in terms of volunteers coming. People went to them. I think maybe one of the things that may have made the physicians feel uncomfortable with Bobbi's presence in the clinic was that a lot of people, when they came to the clinic, simply weren't ready to talk to anybody. A person has to be ready before he or she can take advantage of support service. I had to learn that the hard way.

At one point, we had a patient who was hospitalized and who was having a very difficult time emotionally. I think I referred him to Jim at Shanti, but then I asked Jim if he would come visit him in the hospital. So when Jim came to see him, he hadn't been contacted by this person. The patient felt that it was very invasive to have Jim come to see him, and didn't want to see him. He said, "I don't need any help." [laughter] So the dynamic of people taking the initiative and making the contact themselves, to say, "I would like to go to a support group," or "I want to have a volunteer visit me," was very important.

The Shanti Project actually was funded by the health department at the same time that the AIDS Clinic started at San Francisco General. The city had extra funding and wanted to make it available for AIDS services. They went through Pat Norman's office at the health department. Pat Norman was the coordinator of the Office of Lesbian and Gay Health. She helped to develop the proposal to make the money available. Suddenly there was this money available to the Shanti Project and to San Francisco General to staff an AIDS clinic.

That was the point at which Jim asked me to come work with the Shanti Project. I was hired to start the residence program. The funding determined when community support began to really become official and take shape. Prior to that, there really weren't any support mechanisms.

Bobbi Campbell

Schietinger: Bobbi Campbell, who actually was a nurse at UC at the time, had started to make himself available at the clinic and say, "I want to meet the patients." This was not seen as a friendly gesture by the physicians. They thought he was a little off the wall. They also thought he was kind of out of control. I think somebody called him hysterical. He was

a flamboyant gay man. He was a Sister of Perpetual Indulgence. He was Bobbi Campbell. But he was also very, very serious.

He did make himself available to talk to people and to meet with people, and it was very important for people to know that there was somebody that was functioning even though he had AIDS. He articulated that concept very early and it was important for people with AIDS.

The Health Department's Community Clinics

Schietinger: At the same time that the KS Clinic was happening and Selma Dritz was working in the health department on the epidemiology of AIDS, the health department was utilizing its community clinics as places for screening. These were the places where people came for STD treatment. They had these "AIDS" protocols, and the people that were called the "worried well" were not supposed to come to the KS Clinic; they were supposed to go to the city health department clinics. The doctors there were supposed to be able to screen them and identify if they were really sick or not, and then send them to the KS Clinic if they had suspicious lesions. If they had symptoms of active infection of some sort, I don't know where they were referred before the AIDS Clinic opened at SFGH, because they certainly couldn't be treated in those city clinics for opportunistic infections.

Hughes: Did that system work fairly smoothly?

Schietinger: Well, it gave people a place to go. They were the worried well. These were people who needed emotional support, because they were afraid they were going to die of AIDS, because they had had sex with somebody that was sick. There was nothing to be done, except deal with that. Community Mental Health Services, I believe, did start providing some services to gay men. Oh, gosh, there's a whole--yes, I think there was something happening within Community Mental Health Services, but I don't remember. You should contact Pat Norman to talk about what was happening within the health department in those early days in terms of support services.

Ken Dunnigan, who died a year ago, I believe was the physician at the 17th Street Clinic, which was the main clinic where gay men went. He was a gay man who was very

active in the early days in terms of developing the protocol for the worried well and probably training staff and that sort of thing.

Hughes: Is Pat Norman a health care provider?

Schietinger: She was a psychotherapist who before the epidemic had been the coordinator of the health department's Office of Lesbian and Gay Health. She established the office, and she was there for eight or ten years. I don't know what the ambivalence was around that becoming the office that would coordinate the AIDS funding. Perhaps it was the "AIDS is not a gay disease" struggle. An Office of AIDS Activities that was separate from the Lesbian and Gay Health Office got established when there was funding coming through the health department.¹

Thoughts upon Leaving the Clinic, May 1983

Hughes: Well, Helen, it's really getting late. I think the place to wind up is with those notes you wrote to yourself as you were about to move on to Shanti in May 1983.² [tape interruption as Schietinger reviews notes]

How did you use these notes?

Schietinger: I haven't the foggiest idea. It could have been the basis of a talk. Often, this is the kind of thing that I would do for a presentation. Or it could have just been my attempts to look at the things I learned from this experience. [Studies notes] But this doesn't look like that sort of thing. It looks much more like an assessment that I was trying to do for some purpose.

Ah, this is interesting. It's very interesting that we really did become a center of research with a reputation in the gay community. Oh, yes, an award. The clinic was given an award for community service at the Cable Car Awards,

¹ In July 1983, Mervyn Silverman, health department director, created the Office of AIDS Activities "to consolidate the various Departmental services and activities related to the public health problem of AIDS." Silverman to General Distribution, July 12, 1983. (KSN, 6-12/83)

² [Helen Schietinger]. Accomplishments of clinic. [Handwritten notes, Schietinger personal documents, n.d., circa May 1983.]

which is a big gay event to recognize people and organizations that have done things to contribute to the community. The clinic received an award because it was meeting an important need.

It was impressive how this group of people at the clinic on an informal basis was able to systematically take information and then review it, and decide to stop doing certain studies because they weren't informative. At a certain point, there was a decision made, "Let's not do lymph node biopsies on everybody; we're finding that it doesn't tell us anything. It doesn't help us to treat them unless they're really big or there are other symptoms associated, and we think it might be *Mycobacterium avium* or something."

It was a fishing expedition of necessity, but it also was clinically based to look at ways of impacting patients coming through the clinic.

[reading] "Developed written material for patients, to describe the work-up that was approved by the Educational Materials Committee." I don't even remember that. Oh, yes. I told Angie [Lewis] that I was writing something, that I was saying the same thing over and over again to each person that came through the clinic, and that I wrote it down to be systematic. She said, "Oh, somebody said you can't do that. It has to be approved by the education committee [UCSF Committee on Educational Policy]," or something like that. Anyway, it was reviewed, and then I handed it out to patients, and then it was fine.¹

It took us three to four weeks to get a patient seen at KS Clinic and then to get all the tests done in the staging protocol. I know that there were times when I actually would call to get a biopsy result directly from Dick Sagebiel. If someone was really anxious, I was able to twist his arm to read a result before Thursday, "Please, this one time, just look at this one." And he would do that, so that this person could come in on the day of the clinic and get his results. That was a tough call, because there are only so many times you can ask for that.

I say here in these notes, the members of the KS Study Group contributed to community and professional education.

¹ Schietinger to "Dear Patient," January 4, 1982. (KSN, through 2/82.)

All of us were out there doing lots of talking, both to other care providers in doing in-services, doing rounds, whatever, but also going to speak to various groups in the gay community that really wanted to know what was going on. The clinic was seen as a place people could come to ask questions. I got a lot of calls that were just informational questions in the first year, year and a half, before the AIDS foundation developed a hotline.¹

There was a lot of research that went on. Eventually, tissue was mailed away to other people for research purposes, and sometimes to people with strange theories who did very esoteric things. But the theory was intriguing, so somebody would like the idea and think it was plausible, so they'd come to me and say, "Could you arrange for five samples of normal tissue and abnormal tissue to be sent to this person's lab?" That sort of thing would happen.

We had two protocols going. The contact study was a prospective study of the lovers of people who were being seen in the clinic. But also, there was some blood work for--I can't remember what study it was, but they wanted serum from normal healthy gay men. We made the attempt to have that happen through the 17th Street clinic. A man named Ian Goller approached me and offered to do volunteer work in the clinic. He was from Australia. He recently died of AIDS back in Australia. But he was very active while he was here, and then he went back to Australia and remained very active in making sure that services were available to people with AIDS.

Ian approached me in the first year and said, "I want to help. What can I do? I want to volunteer in the clinic." I wasn't supposed to have lay volunteers in the clinic. They were supposed to come through the volunteer office up at UC. But he actually worked with developing the protocol for obtaining these blood samples from the people that were the "worried well" at the city clinic.

So those things were started in that first year when I was working at the clinic. It's nice that I wrote all this down, because I would have forgotten.

¹ The predecessor of the San Francisco AIDS Foundation, the Kaposi's Sarcoma Research and Education Foundation, was operating an AIDS hotline as of July 1982. (Helen Schietinger to staff in Conant's office, et al., July 21, 1982. KSN 3-12/82) For information about the hotline, see the oral history in this series with Angie Lewis.

Hughes: Yes, thank heavens you did.

Schietinger: I know I felt that certain things needed improving, that the primary physicians lost track of their patients, and that the patients didn't really want to go back to them. This is still a problem in terms of services to people with AIDS. A lot of people would prefer to come to a specialty clinic than to receive care from a "regular doc" in the community.

Hughes: Is that because they feel that they get better care from specialists?

Schietinger: Yes. Especially if the specialists are involved in clinical protocols. If they're already doing research with some of their patients, patients feel that they'll have access to some of the research. So one of the things that I worked on was making sure that there was a copy of the staging work-up, with all of the blood work results, that was given both to the patient and to the referring physician. I actually arranged to have a meeting with the person at the end of the staging process to give him all of his blood results on a piece of paper, and to explain to him what things meant. Most of it was just normal results, which was the very strange thing about it.

I don't know what my last comment here means. "Many studies want OIs [opportunistic infections]--obtain consent to cover AIDS." I think that I had developed a protocol for people coming through the KS Clinic, where they gave informed consent to participate in the research that was being done, and they understood that samples would be taken, et cetera. Researchers were beginning to ask for people who had opportunistic infections, not Kaposi's sarcoma. I was concerned that if we were going to begin to provide access to cases of opportunistic infection, we needed a different informed consent, and we needed to go through the human subjects committee again.

Hughes: Well, it's very late. We should stop. Thank you very much for your time.

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PROFESSIONAL EXPERIENCE

Academy for Educational Development

Technical Director, AIDSCOM (1991-present). Director of technical programs and activities worldwide for the AIDS Public Health Communication Project (AIDSCOM). Provide guidance and monitor implementation and evaluation of technical programs for AIDSCOM programs in Africa, Latin America, and the Caribbean, and Asia. Supervise technical staff in the U.S. and in seven AIDSCOM emphasis country sites. Coordinate management of a technical budget exceeding \$6 million. Coordinate research and intervention studies with cross-regional applications; coordinate diffusion and dissemination of research data and lessons learned from project studies in various professional publications. Specifically, coordinate the drafting of a major public health communication publication that summarizes the state of the methodology as applied to AIDS prevention. Represent AIDSCOM at major national and international AIDS and health conferences.

Regional Coordinator, AIDSCOM (1987-1991). Regional coordinator for AIDSCOM programs in 11 countries in Latin America and the Caribbean. Supervise nine technical staff in the U.S. and in four AIDSCOM emphasis country sites. Manage a regional budget exceeding \$2.5 million. Coordinate research and intervention studies with inter-regional applications, develop intervention activities among individuals with high-risk behaviors, design AIDS communication campaigns that integrate mass media and face-to-face interactions, and disseminate research and intervention findings via professional journal articles, project field notes, and special reports.

In addition to regional management responsibilities, coordinated the writing and production of five major AIDS training guides, including state-of-the-art publications on AIDS prevention counseling, AIDS hotline development and implementation, condom use, social marketing, and use of KABP survey data for AIDS communication campaigns. Also worked with national counterparts to develop AIDS telephone hotlines in Jamaica, St. Vincent, St. Lucia, Grenada, Trinidad and Tobago and to support similar efforts for hotline development in Peru,

Academy for Educational Development (Continued)

El Salvador, Colombia, and Ecuador. As a result, AIDSCOM and USAID have become the primary international organizations for technical assistance and support to AIDS hotlines.

In the Eastern Caribbean, AIDSCOM, with USAID funding, worked with local counterparts to develop and distribute more than 300,000 individual educational materials over a three year period, making AIDSCOM/USAID the primary distributor of AIDS education materials in the region.

Editor/Writer, AIDS Prevention thru Health Promotion Proposal: AIDSCOM (1986-1987). AIDS prevention in developing countries.

Previous Experience

Editor/writer, AIDS Health Project, University of California San Francisco, San Francisco, CA, (1985-1989).

Editor (1986-1987). FOCUS: A Guide to AIDS Research, Working with AIDS: A Resource Guide for Mental Health Professionals, FACE to FACE: A Guide to AIDS Counseling, The Other Crisis: AIDS and Mental Health (video).

Columnist/Reporter, The Advocate (national publication), Los Angeles, CA, (1985-1990). Columnist of The Helquist Report (medical science, health and AIDS research). Reporter for social, political, and special features.

Co-editor, Health Education Research (an international journal), Special AIDS issue, (1987).

Editor, AIDS Project Los Angeles, Los Angeles, CA, (1986-1987). AIDS: A Self-Care Manual.

Script developer and writer, Video Production, (1986). "Native Son: The Story of Bill Pope" (a person with AIDS).

Workshop Facilitator/Presenter, The Shanti Project, San Francisco, CA, (1983-1984).

Previous Experience (Continued)

Freelance Writer/Reporter. Published approximately 500 articles since 1982 in a variety of publications: Ms. Magazine; American Medical News; The Advocate; San Francisco Focus; SF Bay Guardian; Oakland Tribune; California Higher Education; CME Bulletin; New York Native; Washington Blade; Photo Metro; California Magazine; Focus: A Guide to AIDS Research; Health Education Research.

Administrative Assistant, Editor, University of California, San Francisco, CA, (1980-1984).

Consultancies

Consultant, World Health Organization, Global Programme on AIDS, Geneva, Switzerland (1987-1988). Development of AIDS communication publications for use in developing countries.

Consultant/editor, Office of AIDS, California Department Health Services, (contract to AIDS Health Project), Sacramento, CA (1987). Development of Training Materials for HIV Antibody Testing Program.

Consultant/editorial assistance, AIDS Safety Project, School of Dentistry, University of California--San Francisco, (1987). Dental Practice Bulletin.

Consultant, AIDS Health Project, University of California--San Francisco, San Francisco, CA, (1985-1987).

Consultant, San Francisco Department of Public Health, AIDS Activities Office, San Francisco, CA, (1985). Development of component of HIV Antibody Testing Program. Program analysis for review by Centers for Disease Control. Grant writer. AIDS Program auditor.

Consultant, San Francisco AIDS Foundation, San Francisco, CA, (1984-1987). Materials Development. The Family's Guide to AIDS; Getting Your Affairs in Order; Poppers, Your Health, and AIDS. Writing/Development. Media Advertising: HIV Risk Reduction.

Consultant, Hospice of San Francisco, San Francisco, CA, (1985). Advertising/Development Campaign.

Consultant, Hemophilia Council of California, San Diego, CA, (1986). Grant preparation.

Consultant, Rosenberg & Associates, Mill Valley, CA, (1985-1986). Manual for nursing home development in rural areas.

EDUCATION

B.A. (History, Literature), State University of New York at Albany, Albany, New York, 1971.

INTERNATIONAL SERVICE

Canada, Eastern Caribbean, France, Jamaica, The Netherlands, Sweden, Switzerland.

PERSONAL DATA

Birthdate:	April 4, 1949
Citizenship:	United States

HONORS/AWARDS

Invited Abstract Reviewer, Vth and VI International Conferences on AIDS, 1989, and 1990.

Outstanding Achievement, Journalist, Cable Car Awards (San Francisco), 1986.

Nomination, Outstanding Achievement, Journalist, Cable Car Awards (San Francisco), 1985.

PRESENTATIONS

Invited Conference Rapporteur and Presenter, Closing Plenary Session, VI International Conference on AIDS, San Francisco, 1990.

"Daily Conference Report," Commentator, Global Broadcast, VIth International Conference on AIDS, San Francisco, CA, June 1990.

"From Policy to Science: Rapporteur Presentation," VIth International Conference on AIDS, San Francisco, CA, June 1990.

"Communication in HIV Prevention," 1st Regional Workshop on Effective Management of National AIDS Programs, Trinidad and Tobago, July 1989.

"The Rural Theatre Project: AIDS Outreach to the Villages of Trinidad & Tobago," Vth International Conference on AIDS, Montreal, Canada, June 1989

Facing AIDS, a series of three one-hour Canadian national television broadcasts, BCTV, Invited Speaker, Panelist, Vancouver, Canada, 8/87.

"Comprehensive Care of the AIDS Patient," national workshop sponsored by San Francisco General Hospital, Invited Speaker, September 1986.

"AIDS: Metaphor and Reality," International Conference on the Social, Cultural and Political Effects of AIDS and HTLV-III/LAV, Swedish Ministry of Social Affairs and Health, Invited Speaker, October 1986.

INVITED INTERVIEWS

American Broadcasting Corporation

Australian Broadcasting Corporation

Cable News Network

Danish Broadcasting Corporation

National Broadcasting Corporation

Newsweek Magazine

Time Magazine

The Reporter (Stockholm, Sweden)

The Vancouver Sun (Canada)

January, 1983

Largest Lesbian/Gay Circulation in the Bay Area

Mark Feldman: Coming Up!, (January, 1983) A Personal Look at AIDS

by Mark Feldman
as told to Michael Heiquist

On December 10th Mark Feldman addressed an AIDS forum attended by fellow members of Sha'ar Zahav, the lesbian/gay Jewish congregation. He announced that he had AIDS, including KS, and spoke about how these diseases affect his life. When the forum ended, a member rose, and, in thanking Mark, remarked that over the years he had witnessed many of Mark's actions that had made him proud, but nothing so much as his speaking that evening.

Feldman's decision to share this event in his life is consistent with his activism in the gay community. His involvements include political campaigns, fundraising efforts, membership in Alice B. Toklas Club, and leadership roles in Sha'ar Zahav and the Coalition for Human Rights. For the last two years Feldman has focused on the needs of lesbians and gays in his work as Director of Admissions at the New College of California on Valencia Street.

It has now been six weeks since I have known the gloomy news from the medical tests I have been undergoing. The tests confirmed that I have AIDS (Acquired Immune Deficiency Syndrome) and KS (Kaposi's Sarcoma). Many close friends have heard about my test results, and the TELE-Gay communication network has been blowing fuses. In mid-December I was given more information that started the communication process all over again. I also have PCP (Pneumocystis carinii Pneumonia).

My purpose is more than to spread the news but rather to communicate a few things from the unique position I find myself in. Regarding my illness, I have come to some initial terms with it. Many of my friends marvel at my courage and good attitude (frankly, I have surprised myself at my ability to be strong when necessary). There have also been moments when the whole world has turned to Jell-O, when I pull the bedclothes over my head and wish it would all go away (and the sheets are never long enough). Other KS, AIDS, PCP patients have had different reactions to their situations. However, I feel that this damn thing has rarely been addressed on a *personal* basis, especially in the media. It is presented as a "gay plague" or "homosexuals get it"—but what about human beings? Where are they? *Who* are they?

I feel that almost everything I have done in my life has been somehow linked to giving and getting love and support. I would deny all my life's hopes, dreams, and visions if I therefore didn't try to turn this mess into a contribution. Believe me, I've been ready several times to pack up and escape to my special beach in Hawaii, or to tell everyone to go jump in a lake. So far, my personal commitment to educate, communicate, and grow with everyone (straight and gay) has held up. My diseases are a holistic problem in my



life. It's not just a medical problem. My whole life is being affected, my relationships, my community life, my professional interests. In addition to my treatments at UC San Francisco, I'm pursuing other therapies. These include biofeedback, acupuncture, nutrition, vitamin analysis, counseling with my therapist and also with a volunteer from Shanti. But I'm trying to lead as normal a life as possible. I've stepped back from some involvements, but I do not want to be isolated from my friends or restricted from my community.

This is my first major medical crisis. I've never had any broken bones or stitches, I've never been hospitalized. Most of the doctors currently treating me have been wonderful, but some need to be reminded of what's happening to me. I am more than an object of research, and I remind the doctors and nurses when necessary. I've decided to put on a happy face, to adopt a cheerful attitude. It helps the process for me. It also helps the doctors and nurses. These procedures are not easy on them either.

If you or your friends are confronted with AIDS, you must put a lot of faith in medical care; but remember also to trust yourself. Ask questions about tests: what is this one for? how does it relate to other tests? There are choices about what is being done. Remember also—or keep a list—of what tests have been given. A number of medical personnel will be working on the case. They may need to be reminded to check the medical record frequently to stay current.

My therapist reminded me that the news of my disease may be the most important event of the year in the lives of my friends and family. It's been very difficult sharing this

(continued on page 2)

Mark Feldman *(continued from front page)*

news, and I know the pain that's occurred to those I've told. You never know how people are going to react, but nearly all have offered their support and love. I have confronted a few friends about their reactions. Some have needed some signals from me to be able to release the jumble of emotions they're experiencing.

Friends and relatives have offered every imaginable type of help (But *no one* is willing to do windows!) It's important to me to maintain a certain daily normalcy during this crazy time. My friends and family experience a certain helplessness. However, their support and love could not be appreciated more. I want to mention also my counselor from Shanti, Steve Tripp, has been incredibly helpful. Just having his company during some of my visits to the doctors has helped a lot.

I am having problems setting long-term goals. (I'm thinking of years, not months). Having recently ended a five year relationship, I was looking forward to a period of personal discovery and freedom. But AIDS interrupted that. When I realized I was sick with AIDS, I began setting goals, e.g. continuing with my PhD, traveling to Europe, etc. I felt I needed to do these things as something I *should* do for myself. But now I'm feeling less compulsive and I'm focusing on what I *really* want and need to do for myself.

My personal philosophy, when I'm clear is that *what* are all going to die. This is a life-threatening event that has come earlier than I expected. I don't know why this is happening. The doctors don't understand this disease. So why take the cause of it personally? I've decided against tormenting myself with questions of "what have I done in my life?" or "what is it in my lifestyle?" For those who wonder about the basics, I will say that I don't smoke or drink coffee. I've done very little drugs; my sexual life has been moderate.

I'm trying to focus more on wellness than on illness. I've developed more of a day to day attitude. I try to appreciate my gift of life each day. And this event does fit into my quest to discover more of human nature.

For all of us there is, in a crazy way, an opportunity for growth out of all this. The real truth for me of the Stonewall Revolution was that for once we refused to hide from the world and from each other. I stood outside that bar almost 14 years ago in horror as that first drag queen swung the first parking meter at a cop. I learned my lesson. Anita Bryant and Jerry Falwell with all their horror got us to link arms as humans: sisters and brothers. This new crisis we are *all* faced with is a lulu, but I, for one, intend to keep it as much as I can on the personal level and not get completely lost in a sea of gay or straight statistics, medical terms, the misinformation of the media, and most of all, fear. I never want to let go of the hands of my sisters and brothers, my friends, my family that we have fought so hard to hold.

"L'Chayim" ("To Life")
Mark Feldman

Response Tactics

Now for the good ideas. Not from some nameless reporter, but from me, Mark Feldman. First of all, I do not claim to have all the answers. Nobody at this point has *all* the answers and be wary of anybody who claims to have them. On the other hand, each of us has the gift of common sense and good judgement. It's not a bad time to put these qualities to work. For example:

1) **KNOW THE SYMPTOMS** (including enlarged lymph nodes; a persistent, dry cough not from smoking; chills; fever; unexplained weight loss; suspicious lesions).

2) **GET TO KNOW YOUR BODY INTIMATELY** (Showers are excellent times for more than singing). I had all the above symptoms other than the lesions, kept an active inspection schedule, was examined thoroughly by my doctor, and I discovered the two little non-painful, sensation-free KS buggers in the roof of my mouth totally by accident).

3) **GET ADVICE AND SUPPORT.** If you notice these symptoms and (please be aware of the closet hypochondriac in most of us), contact your doctor or the KS Foundation at (415) 864-4376 TODAY.

4) **EDUCATE YOURSELF AND YOUR FRIENDS** with the information we do know. Contact the KS Foundation or other knowledgeable sources for information.

5) **GIVE!** Reach really deep into your pockets and dig. Our friends in Washington are having a hell of a time squeezing out money for more research (let alone education and personal services). We need to take the ball and run with it. And don't forget to write and express your concerns about AIDS to your elected representatives.

6) **CHALLENGE RUMORS AND CALL FOR FACTS** (in a supportive way). Give the evil eye and challenge those who say things like: (a) "Women don't get AIDS" (about 5% of AIDS people are women). (b) "It's a gay plague" (25% of AIDS people are not lesbian or gay. It's not a plague; it's an epidemic). (c) "I know someone who was cured." (Sorry, right now there is no cure, only symptom alleviation). (d) from some lesbians: "This is *their* problem." (Simply not true. And many lesbians are actively working on this. Everyone's help is greatly needed).

7) **STAMP OUT GUILT, SHAME, AND BLAME.** No one knows the full story yet on what causes AIDS or why a host of diseases takes advantage of certain weakened immune systems. So there's no reason for guilt.

8) **LIVE WELL!** Get plenty of rest; eat well; reduce stress where possible (good luck); practice good sexual hygiene; and use common sense in your sex life. The last one is a hot potato. Remember: SEX does not cause AIDS...DISEASE (of some kind) causes AIDS. So don't avoid sex, but *do* try to limit your activities to people you know. Ask them how their health is, and share your state. Your goal should be to avoid *any* Sexually Transmitted Disease, not to create a generation of celibates, nor to foster stupidity. Use your good common sense.

9) GET HEALTH INSURANCE. If you don't have it, get it. My own good coverage has saved me a lot of grief.

10) KEEP YOUR SENSE OF HUMOR. Let me tell you, it helps a lot.

11) SAY A PRAYER FOR EVERYONE OUT THERE WORKING THEIR TAILS OFF TO DO SOMETHING ABOUT THIS.

Mark has recently addressed several groups and conferences, both gay and straight. At each occasion he has been forthright and candid about his diseases. He expresses his own deep emotional responses, but he is always quick to balance the emotion with his particular black humor. He offers to show his KS lesions, which are on his palate. As he tilts his head back, he requests an admissions charge. When he suggested writing about his diseases, he proposed a title: KAPOS! DEAREST. Mark enthusiastically supports the KS fund drives and offers himself to be the KS Poster Boy. Exhorting others to keep their sense of humor, he recognizes the dark turn his has taken. To those who are offended by it, he says simply, "Tough Luck."

Mark is not hiding behind his humor. He also speaks of his fear and of the pain during some of his medical tests. But he seems to know instinctively that reasonable fear can lead to panic and that pain can encourage despair.

One early evening in mid-December Mark was driving me to his house. We were on 20th Street by Dolores Park. He slowed the car so we could watch the sun set over the city. I sensed a special poignancy in this. Mark has seldom spoken of a limited future; he has simply chosen to focus on the present moment. I feel privileged and pained to share these moments with Mark. I have discovered deeper personal sources of strength and determination as a result of witnessing his courage. I believe Mark is showing all of us an effective means of facing this dilemma.

Mark's list of suggestions should be more than glanced at. He is suggesting that many of us CHANGE our habits for better health.

There are other specific responses available. Bill Shear, PhD, a business partner of Feldman's, is about to launch a full scale, raffle ticket fund-raiser. This will be a major effort in conjunction with the Shanti organization and perhaps others. Current plans call for a first prize of \$100,000. Tickets will be \$10 each. If that sounds like a lot, consider what we're up against. Proceeds will be directed at support services for individuals affected by AIDS. These services will focus on individual, personal needs. The fundraiser will be a means of taking care of ourselves while we continue to lobby for more research money from the government. More details will be forthcoming. Bill Shear may be contacted at (415) 383-5426. There is a need for start-up money/loans.

Volunteers and contributions are needed both by the KS Foundation (864-4376) and by Shanti (558-9644). If you're feeling stressed and scared by all this news, consider speaking with a Shanti counselor.

COMING UP!

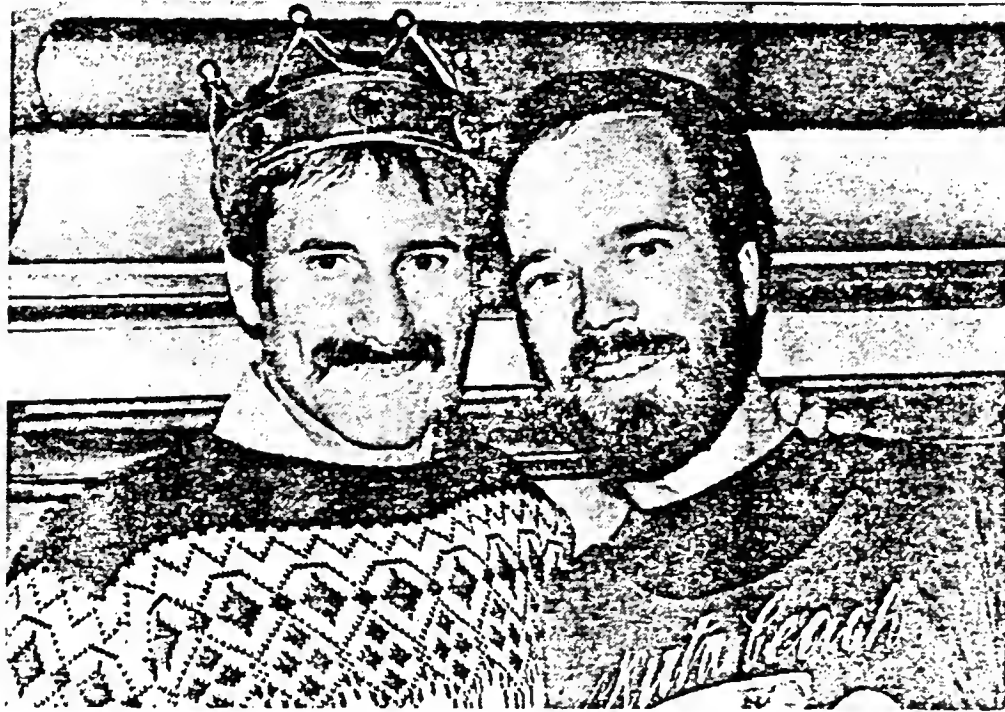
Largest Lesbian/Gay Circulation in the Bay Area

FREE

Reprinted By Permission, Coming Up!, September 1983

AIDS and Grief: Coming Up! A Personal Experience (March, 1983)

By Michael Helquist, © 1983



"Michael, I think we need a miracle this time."

"Mark, what if we got it? What if you were out of the hospital and cured of AIDS? We could go traveling. You know where we could go?"

"Where?"

"First, I'd take you to the Greek islands because I've always wanted to go there. Then you could take me to your favorite beach in Hawaii."

A little later.

"You know, Michael, you can still go to those places. I don't know where I'm going from here. But I just might be there waiting for you."

—May, 1983

IT'S BEEN THREE months now. Already. Mark Feldman died of AIDS complications on Thursday, June 2nd. I have little time perspective on those six and a half months from November of '82 (the date of his diagnosis) to June of '83. It seems like yesterday; it seems like never. In six months' time I came to care deeply for Mark as a friend, a boyfriend, and a lover. And now he's gone.

Mark chose to play a very important role in making public the personal side of an AIDS diagnosis. He helped others see beyond the medical reports and statistics. There are, of course, more than AIDS diagnoses hitting the gay male population. Some men also face death and dying. Even greater numbers of gay men and lesbians confront troubling sensations of loss and tremendous feelings of grief.

My experiences with Mark were personal and

unique. They do not necessarily apply to others. I do think that it's important to acknowledge the considerable pain and grief in the community now. I believe it's important to be sensitive and supportive of these feelings.

SENSATIONS OF SHOCK combined with my fear of grief to block much of the inevitable grieving process. Early in August of this year, two months after Mark's death, things began to get out of my control.

I was asked to address a new group of Shanti Project counselors about the grieving process. The day was difficult for me. I had successfully held back much of the pain of loss for weeks, but the pressure for release was building. After I spoke to the group, there was an exercise, a sort of guided meditation, that Shanti employs called "letting go of grief." Even the title scared me. I didn't know if I could handle the pain; it

seemed like too much. I also feared that if I let go of the grief, I would be letting go of Mark. I went ahead with the exercise: it allowed me to release just a little bit of the pressure I felt. And I was O.K. afterwards.

Soon after the Shanti training, I experienced a great deal of pain following a medical procedure. It was the most intense physical pain I had ever endured. These physical problems coincided with my growing sense of emotional pain and loss for Mark. I was unable to hold in the feelings any longer. With my grief for Mark there also occurred the withdrawal of a new friend's valued comfort and companionship. The thought of the second loss triggered the immensity of the first. My physical resources were at their lowest ebb. The pain killers I was taking after my operation altered my perspective, and I got very depressed. I was in a sorry state.

On one of these difficult nights I had trouble sleeping. The pain kept me awake. I got up to take another pain killer. I returned to my bed, feeling lonely and sad and hurt. I pulled up the blankets, rolled to one side, and thought of Mark. I imagined him lying there in bed next to me. I snuggled up closer to him and put my arms around him. I remembered staying overnight at his house several nights during the last months. We would hold each other and feel safe for a few moments. I remembered our through-the-night conversations, in-between his violent coughing spells. We would tell sleep-tossed stories, and I'd rub his back. And now, during my difficult night, I felt safe and secure with my thoughts of living next to him.

That evening provided me with a valuable insight. When I called upon the memory of sleeping near Mark, I felt I was calling upon his spirit and energy, on our shared love and support—all those things still available to me. I began to realize that only when I let the grief out and feel it will I begin to get to the other side, that of enjoying my memories of Mark. I started to tell friends that I wanted to let go of Mark's death. His death was tragic and heartrending; it hurt me more than anything I had ever experienced. But his death was an event that had passed. I wanted to begin to cherish more fully his life.

THE ACTUAL GRIEVING had begun many months ago, even before Mark's death. There had been losses along the way. In May of 1983 after the Candlelight March, Mark and I realized that we would not be attending the Denver AIDS Forum together in June. He would not be well enough. Mark and I didn't have time to take trips together. I enjoyed the stories he and his friends would tell about past travels, but realized that traveling would not be part of my experience with Mark. We would never visit, as planned, his friend's iris beds or his favorite beach in Hawaii.

There was a loss of physical intimacy. Sexual sharing had been curtailed many months earlier. There were times in the hospital when Mark and I were alone together, and Mark would ask me to lie next to him, just for him to be physically close to someone. But there was also the occasion when he suggested that we no longer sleep

together in his bed at home. He thought he would be more comfortable with more bed space. I felt a little more loss.

Most directly I grieved while watching his condition deteriorate. Some men with AIDS remain in stable condition; Mark wasn't one of them. He didn't have an easy time with any of his medical tests and treatments. They all seemed to be hard on him. There are what I call my "horror stories" about which I won't write. But the horror occurred when I saw things that made me feel intuitively that Mark wasn't going to be able to get over this disease.

Reviewing my journal of last year, I noted that on Christmas Eve after dinner with good friends, I came home feeling overwhelmed with sadness. Earlier that day I had visited with Mark before he departed to visit his family in New York. A rash had broken out all over his body. It was a reaction to the medication for pneumocystis. He seemed so vulnerable and upset. I hadn't seen him so shaken before. My feelings of sadness and incredible anger stayed with me throughout the day. When I returned home late that evening, I sat next to my Christmas tree lit up in the dark and reached for the phone. I called my Shanti counselor and told him, "I don't know what to do with this grief." We talked about it for awhile, and he was both encouraging and supportive. I was relieved that he was available for this and other calls. But I still asked, "Where can I put this grief? If Mark gets worse, there's lots more to come." And that was only the end of 1982.

I WAS WITH MARK when he died. So were his mother, Ruth; his close friend, Stuart; his Shanti counselor, Stephen; and his doctor, Steve. We knew, but with complete disbelief, that the end was near. Mark was not talking; there was no eye contact. His breathing was extremely labored. I knew I was waiting for his last breath, and I hated that thought. I had promised Mark that I would stay with him throughout this ordeal. I believe he waited until we had all gathered around him. I think Mark had prepared himself and was ready to let go peacefully. But I wasn't ready; I hadn't kept up with him.

Stephen suggested that I might want to say good-bye to Mark. The thought was devastating. At first I thought, "No, everything is resolved between us." But then I wanted to—all confusion and rebellion inside—and I stood up, leaned over the bed; and, as I had so often before, kissed him on the forehead, told him I loved him, and said good-bye. Soon thereafter, his breathing stopped. Mark had let go. He had fought enough, and his peace was well-deserved.

MARK'S FUNERAL WAS held in New York on Sunday, June 5th. I had given Mark's mother a framed copy of the only photo I have of Mark and me, taken last March. On the reverse side of the photo I had written to Mark some private thoughts which I realized would never be seen again. The photo, special items from special relatives and friends, were buried

with him, as was the crown that a close friend had made for him, which Mark wore the day of the Candlelight March.

On the day of the funeral, at the same time I stayed home alone here in San Francisco, wanting to be aware of Mark in my thoughts and feelings. I lit a candle and played some of my favorite music. I re-read part of a fairy tale I had read to him a few days earlier in the middle of a sleepless hospital night. I cried for Mark and I cried for me, his family, and his friends. I remembered the special moments Mark and I had together. Finally, I was still and calm, just the flickering candle and the music, and I felt some peace. The ordeal of Mark's fight was over. I imagined his being laid to rest, like a seed.

By the time of Mark's San Francisco memorial service three days later, I felt that I had already had my service for Mark. This one was for the public, for the larger family of Mark's friends. The Congregation Sha'ar Zahav organized and offered a moving and healing service. I felt a connection and a need then to be public myself.

As I had come to be associated with Mark, I wanted people to realize that, of course, we collectively move along. There is continuous change. I sensed the useful role of widow/widower as a link between the past and the present and as a step from the present to the future. With the funeral and memorial service completed, and later with the closing of Mark's estate, there occurred the more or less official ending to the public grieving. For many, of course, it was the mid-point for much private grieving.

MANY OF US HAVE so little experience with grieving and with the realities of death. We're often separated by lack of understanding from our families. Those of us who are young have often allowed ourselves to be cut off from older gays and lesbians who could perhaps share their insight into these life experiences. We don't seem to have any sub-cultural, meaningful traditions for our grieving.

This was certainly true before anyone knew of AIDS. Death has not been a stranger to the gay population, but to many it seems death has never been so pervasive. It is this pervasiveness that makes AIDS grief different. Who do we mourn next? And there are so many of us in our 20's and 30's who now mourn the loss of friends, brothers, and lovers—many also the same age.

One of my more surprising feelings soon after Mark's death was a flash of fury directed at Jackie Kennedy Onassis. Although she had a moment of panic during the assassination of the late president, she generally is remembered as the strong, silent widow standing tall with a humble dignity. That wasn't the kind of mourning I had in mind. I wanted to go out into the darkness and rage against the sky and stars, to whatever or whoever had allowed this tragedy to descend.

I've been trying to find my own way through this. I talk with my men and women friends, my Shanti counselor, my therapist. Weeks after Mark's death, I would walk through my days, functioning

on a minimal level. I felt confused, alone, and disoriented. I wondered, "Is this part of the grief?" I would recognize grief in my crying, but I wonder about the meaning of so much confusion and insecurity in my life.

I thought of Mark every day; I missed him every day. Somehow every Thursday near 4 pm (the day and time of his death) I would be especially reminded of him. On a few Thursday afternoons I would even be driving Mark's car at St. Franklin Hospital where he died.

Mark had been very skillful last winter and was bringing the focus of the media to AIDS. He gave endless interviews to

newspapers and to radio and TV stations. His photo was featured in *Newsweek* and the German magazine, *Der Spiegel*. After his death, the legacy of Mark's activism left me and many others in a curious conflicted position. It was impossible throughout the months of June and July to pick up a gay newspaper or newsletter without seeing a photo of Mark or reading a reference to him. Local AIDS TV specials featured clips of Mark's speaking from his hospital bed or speaking from the stage the night of the Candlelight March. I want Mark and his courage and example to others to be remembered. At the time however, I felt intrud-

ed upon by these photos, articles, and feature programs. I had no control over how or when the issues of Mark's absence and my grief would be thrown at me.

With the lack of any community guidelines, I confronted a variety of responses from individuals. Some would know just what to do, and a quick hug would replace any initial awkward words. Others would avoid me, as they later explained, because they didn't know what to say. Some would become noticeably uncomfortable if I mentioned Mark in casual conversation or if sometimes I spoke of him in the present tense.

As the weeks passed I began to get more

Notes for Coping

Some people diagnosed with AIDS develop serious medical consequences than others. When tests, treatments, and hospitalizations become frequent, the life of the person with AIDS and the lives of loved ones lose their normal daily patterns and often become very difficult. The following are some ideas and suggestions that may be helpful to the AIDS person and those in the immediate circle of family and friends.

PATIENT ADVOCACY

Confronting the medical establishment can be overwhelming for a person in good health. The unknowns about AIDS often mean that there are numerous tests, reports and opinions. It can be helpful to have one or two other persons come to the patient to listen to the doctor's reports, ask questions and take notes. Information can help reduce fear.

Doctors, friends and relatives can also help establish a rapport with the medical staff in the doctor's office or hospital. Let the staff know you are interested, and that you will politely but firmly follow through to fulfill the needs of the patient. Become a partner in the medical

There is room for assertiveness in the hospital. Institutions have their own daily routines that don't work best for the hospital. Sometimes the routine may not be the best for the patient. For example, a patient's room does not have a cleaned at a given moment; the staff can be requested to wait 20 minutes. The patient can ask for maximum privacy—not only from visitors, but also from staff.

HOSPITAL ROOM

In the hospital room, you may want your surroundings to be as pleasant as possible. Considering how much the room costs, you might want all! Flowers, music, balloons, your own food, etc. Sometimes it may be more appropriate for not talking, and some visitors may need to learn to be comfortable with this. Quiet background music can be soothing, perhaps a massage, or just quietly holding hands.

GETTING OUT INFORMATION

It might be helpful for one or two individuals close to the person with AIDS to serve as a contact for the larger group of friends and acquaintances who are concerned about medical developments. These contacts may want to make their phone numbers available for others to call them. There's a delicate balance here between getting overwhelmed with questions and disseminating needed information.

INSURANCE FORMS, etc.

It may not be possible or desirable for the person with AIDS to be responsible for completing all the insurance forms, disability forms, etc. One other person could relieve much pressure by assuming this role of "taking care of business." Perhaps another person could "monitor" non-medical mail for important bills, checks, letters.

One person might also keep track of the medications, which drugs are to be taken, when. Questions may arise: Is it alright to take another pain killer now? When was the last one taken? The primary support individuals should also know—and have it in writing—who to call in time of emergency—family, doctors, friends.

These arrangements depend, of course, on the needs and desires of the person with AIDS.

PHONE MACHINE

A phone answering machine can be very helpful. Sometimes the AIDS person is simply too tired to answer the phone each time it rings. Sometimes a call from the doctor may be pending, so it would be better to monitor calls before lifting the receiver. Also, the message the AIDS person records on the machine can tell friends how he's generally feeling, when to call back, etc. If the person is hospitalized, there might be a recommended suggestion not to visit for a day or two. The phone machine can simply be a means for limited but less-demanding communication.

MASS MAILING

If there are many friends and relatives from all over the city and country sending cards and inquiries, it might be helpful to answer with a "mass mailing," one general letter sent to all. In the letter the person with AIDS can, of course, give personal news, but the letter can also be an opportunity to inform about research, the need to pressure politicians for funding, and agencies appropriate for contributions.

PERSONAL AFFAIRS

Setting personal affairs in order is a good idea for the most healthy among us. Is there a current will? Who knows where it's kept? Is there a listing of bank accounts, charge accounts, investments, property titles, insurance coverage, outstanding loans, etc?

FOR THE LOVER, RELATIVE, CLOSE FRIEND

I imagine each occasion presents a unique set of circumstances, so I will be personal here. There can develop a tremendous intensity of experience for a person close to someone fighting AIDS. This intensity can sometimes overshadow and even seemingly diminish other relationships. I lost contact temporarily with a few people close to me as Mark's condition worsened. Many of my days focused on getting to work, getting to the hospital, and getting to bed (not "home," just bed).

What can others do to help those who are in positions of primary support? Be gentle. Your friends are probably experiencing great internal and external pressures. Let them know—remind them—that you're nearby. They, too, may need help with meal preparation, grocery shopping, etc. You may be in a position to help them acknowledge their fears, pain and hurt. They may be scared to "let go" of their feelings some, even when they need the release the most.

For the lover, relative, close friend: Consider your limits and your capabilities for handling stress. During times of emotional and physical stress, withdrawal, however well-intentioned or needed, can feel like rejection to the person left behind. If possible, determine your capabilities for responding to crises and be consistent with your response, with your time, and with your energy. Be dependable at the level of your capability.

For the loved ones, it can be difficult to take care of yourself while you are so focused on your special person who has AIDS. You may need to let others help and support you. Sometimes their perspectives on your needs may be more insightful than your own. Also, consider that while other relationships and interests may have diminished in relation to the intensity you now experience, those people and pursuits were a valuable part of your life and most likely will continue to be.

Take care of yourself as best you can.

Michael Helquist, © 1983

AIDS and Grief: A Personal Experience

messages. Now a few acquaintances would suggest that it really was time for me "to get on with it." I was told, "Life must go on. Get out and have some fun. Meet someone new." Ironically, others would wonder aloud how I could possibly think of feeling affectionate or loving to another man so soon. What I wanted most at the time was for someone to understand that I was confused, that I needed some comfort, and that I wanted to talk—frequently about Mark. During Mark's last six months of being in and out of hospitals, on and off treatment programs, there usually wasn't the time for any of us to really discuss what was happening. Too much happened too fast. There was no normal time.

My experiences of witnessing death and confronting grief convinces me that there is often a lack of awareness and sensitivity, but mostly a lack of understanding, among our gay population of what is unfortunately going on here. That we have immense good will and that we have responded to the AIDS crisis with courage, devotion and determination I don't question for a moment. I just find that once again, we have another need pulling at our consciousness.

WHAT CAN I SAY to those of you who fear that you will soon share my experience of losing a loved one to AIDS? Or to those of you who have already lost someone? What can we say to each other? There may not be much need for words: the most intense feelings are shared and understood. Opening ourselves to love takes on a special meaning, to others this may sound like an outdated cliché.

I will simply say what I have learned to this point, three months later. My grief and the intensity of it are very important to me; it is a reflection of my deep feelings for Mark. My grief is my own experience. I won't follow anyone else's patterns or expectations. Only I will know how long my grieving should continue. I may, however, seek out the observations of others to achieve some perspective. I will seek comfort where I'm able and when I choose. I still have both the *need* and the *capability* to give and receive love, to be affectionate and intimate, to be sexual.

I remember Mark's telling me, "Michael, this disease is mine. You can't experience it the way I do." Now I think this grieving is mine. I want

and need to share some of it with others; but it is my own experience to feel and from which to learn. I feel that I've reached a stage, a phase in the process of grieving, of opening myself to the experience of death and to the immensity of life. AIDS and the losses associated with it have been too intense for me to handle with my formerly adequate self-sufficiency. I have painfully experienced many personal limitations, and I'm now looking in new directions. My life feels changed, and yet I'm just standing on the edge of the changes. It looks pretty frightening out there. I've never felt a greater challenge ahead of me or one with greater opportunities.

I'm very thankful that I'm not alone in this process. I have good men and women friends who understand, and we care deeply for each other. And I have an ally, my Mark, my Jewish American Prince, wearing his crown and nudging me forward. If Mark is on those Greek and Hawaiian islands someday when I travel there, I want to be ready to open my heart to him with joy and more love.

L'Chaim. To Life.

CITY AND COUNTY OF SAN FRANCISCO

**BOARD OF SUPERVISORS**

CITY HALL, SAN FRANCISCO 94102 • TELEPHONE 558-3184

June 8, 1983

Mr. Michael Helquist
303 Coleridge
San Francisco, California 94110

Dear Mr. Helquist:

This is to inform you that, upon motion made by Supervisor Richard Hongisto, joined by Supervisors Louise H. Renne, Harry G. Britt, Carol Ruth Silver and John L. Molinari, the Board of Supervisors adjourned its regular meeting of June 6, 1983 out of respect to the memory of the late Mark Feldman.

The members of the Board, with a profound sense of civic and personal loss, are conscious of the many fine qualities of heart and mind which distinguished and brought justifiable appreciation to Mark Feldman in the community.

The Supervisors realize that mere words can mean so little to you at a time such as this, but they do want you and the members of your family to know of their deep sympathy and heartfelt condolence.

Sincerely,

A handwritten signature in dark ink, appearing to read "John L. Taylor".

John L. Taylor
Clerk of the Board



Marcus A. Conant's Kaposi's sarcoma notebook,
1/84-12/95, AIDS History Project,
Special Collections, UCSF Archives

March 24, 1985

Mr. Michael Helquist
c/o "Coming Up" Magazine
867 Valencia St.
San Francisco, CA 94110

Dear Mike:

Thank you for sending me your article in the March "Coming Up". I did not see Leonard Calabrese's study, and would appreciate your dropping me a note with the reference. This study is very similar to one that we conducted here in San Francisco and that I will present at the International AIDS Meeting in Atlanta next month. I would like to reference Calabrese's study in my presentation, if possible.

I was pleased to see your reference about the review of the public health service's response to AIDS that was prepared by the Office of Technical Assessment in February. I would hope that you would give a detailed analysis of that report in your next Science article. I think that the report clearly demonstrates that the amount of support for AIDS activities provided by the federal government has not been equivalent to the effort that individual researchers from the public health service felt was necessary to stop this epidemic. Further, I think it is scandalous that public education funding has been reduced from \$200,000 in fiscal 1984 to \$120,000 in fiscal 1985. Even if the government does not care about the homosexual community, \$120,000 is not ample funding to mount the type of educational program that will be necessary to limit transmission of the disease into other segments of the population.

This technical memorandum again clearly demonstrates that the Dept. of Health and Human Services was negligent in its duty to the American public by not appointing a blue ribbon commission to coordinate the research and educational activities that this new and unexpected epidemic created for the American public. The fact that the government "did not take into account the social implications and ethical dilemmas that would have to be addressed when persons who might be carriers of the HTLV-III virus were identified through blood tests" is shameful. Furthermore, let me urge you to encourage your readers to write to the Office of Technical Assessment, Washington, DC, 20510 for copies of this memorandum. A wide distribution of this important document would be of the greatest benefit to the gay community.

As we stressed to Congress in the summer of 1983, a coordinated effort under the Dept. of Health and Human Services could assure the rapid funding of promising proposals and serve to

- KS Notebook

Mr. Michael Helquist
March 24, 1985

p. 2

coordinate the activities of federal agencies, university laboratories and private industry. The fact that our government has not seen fit to develop such a blue ribbon commission is deplorable, but the fact that the Reagan administration has failed in its responsibility to the American people to date does not mean that we should cease our pressure to inform them of the advantages of this type of coordinated response. The rapid development of an effective vaccine is going to take the best efforts of government scientists, university laboratories and private industry. Only a coordinated effort at the highest levels of government will insure that we will be successful in this endeavor in the shortest possible time.

Let me also call to your attention the editorial that appeared in this week's Science by Dr. Daniel Koshland, the editor of that highly respected journal. Dr. Koshland points out that the threat of lawsuits has virtually throttled the production of vaccines by American manufacturers, and we may soon face the dilemma where the vaccine for AIDS has been created and no one is willing to produce it for the American market. While this issue is remote today, it may be of critical importance 6-8 months from now if a vaccine to the AIDS retrovirus can be developed.

Sincerely yours,

Marcus A. Conant, M.D.

MAC/ds

Enclosure: photocopy of article in Science by Dr. Koshland

Jeannee Parker Martin, RN, MPH

Jeannee Parker Martin, RN, MPH

6811 W. 63rd Street, Suite 221 • Overland Park, Kansas 66202

Education

- 1983 Yale University School of Epidemiology and Public Health
Master's Degree in Public Health, Health Services Administration, emphasis on management and evaluation of local health services.
- 1978 Georgetown University School of Nursing, Washington, D.C.
Bachelor of Science in Nursing, emphasis on community health nursing services.
- 1975 Universidad Catolica, Quito, Ecuador
Georgetown University School for Summer and Continuing Education Summer Study.
Anthropology and Spanish Literature.
- Certified Zenger-Miller Trainer in Continuous Quality Improvement.

Professional Appointments

- Present Vice President
The Corridor Group, Inc., Overland Park, KS
- 1984 - 1994 Visiting Nurses and Hospice of San Francisco,
San Francisco, CA
Executive Director (1991 - 1994)
Executive Director, Hospice Programs (1986 - 1991)
Director, AIDS Home Care and Hospice Program, (1984-1991)
- 1983 - 1984 AIDS Program Coordinator,
Yale New Haven Hospital,
New Haven, CT
- 1982 Associate Administrator,
Catholic Relief Services,
Phanat Nikhom Refugee Camp, Thailand

Jeannee Parker Martin, RN, MPH

6811 W. 63rd Street, Suite 221 • Overland Park, Kansas 66202

Professional Appointments (cont'd.)

- | | |
|-------------|---|
| 1981 - 1982 | Coordinator,
Georgetown Organization for Latin American Concern,
Columbia, South America - The Dominican Republic |
| 1979 - 1981 | Assistant Nursing Coordinator,
Georgetown University Hospital,
Washington, D.C. |
| 1977 - 1981 | Coordinator,
Coordinator & Teaching Assistant,
Georgetown University Office of International Programs
Washington, DC |
| | Senior Nursing Practicum,
Student Nurse representative to the Center for Family Integration, Guatemala,
Central America |

Professional Affiliations

- American Public Health Association
- California Association for Health Services at Home
- California Public Health Association
- Hospice Association of America, Former Board Member
- National Association for Home Care, Former Board Member
- National Hospice Organization
- Sigma Theta Tau Nursing Honor Society

Awards And Recognition

- Office of the Mayor, City and County of San Francisco, Proclamation for Service to the Community, 1994
- California Association for Health Services at Home, 1992 Lillian O'Brien Award
- National Association for Home Care, 1992 Special Recognition in Hospice
- Cable Car Awards, 1992 Bob Cramer Award of Excellence
- Georgetown University School of Nursing, 1988 Distinguished Alumnae Award

Publications

The following is a selection of Ms. Martin's publications. A complete listing is available upon request.

Martin JP. *Transitioning to Home Care: A Core Curriculum for Health Care Providers*.
Sacramento, California: California Association for Health Services at Home, 1994.

Jeannee Parker Martin, RN, MPH

6811 W. 63rd Street, Suite 221 * Overland Park, Kansas 66202

Martin JP. Acquired Immunodeficiency Syndrome. *Core Curriculum for Home Health Care Nursing*. Gaithersburg, Maryland: Aspen Publishers, Inc. 1993. 1995 edition pending.

Martin JP, Hughes AM, Franks P. *The AIDS Home Care and Hospice Manual*. San Francisco: Visiting Nurses and Hospice of San Francisco, 1990.

Lusby G, Martin JP, Schietinger H. Infection control at home. *The American Journal of Hospice Care*. 1986;3:24-7.

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VNA OF SAN FRANCISCO
225 - 30TH STREET
SAN FRANCISCO, CA. 94131
(415) 285-5615

June 4, 1984

Paul A. Volberding, M.D.
Director, AIDS/KS Clinic
San Francisco General Hospital
1001 Potrero
San Francisco, CA. 94110

San Francisco General Hospital,
Ward 86 Archives, carton 1,
folder: Letters to Paul Volberding, A-J,
1984, AIDS History Project Archives,
Special Collections, UCSF Library

Dear Dr. Volberding:

I have received your letter expressing concern about our change in policy regarding care for Medi-Cal patients. I was out of the country when your letter arrived, so I have not been able to respond to it earlier.

We at VNA of San Francisco share your concern about limitations in availability of care for people with AIDS who are covered by Medi-Cal. Because of our concern we have submitted a proposal to the City of San Francisco to establish a separate Home Care and Hospice Unit for AIDS patients. We have requested that this unit be funded on a program budget basis, rather than by fee for service. VNA of San Francisco would then bill Medi-Cal and private insurers for whatever reimbursement could be collected and return to the City whatever can be collected.

Enclosed is a summary of the proposal that we have prepared for consideration by the City. The proposal is now being reviewed by the AIDS Activity Office for their comments and suggestions for revision. As we progress with this process, we will keep you informed.

Because we share your concern about the needs of people with AIDS, we would be happy to work with you in whatever way we can to provide home and hospice care for patients with AIDS. We would like to make it possible to keep them out of the hospital, in their own homes with their loved ones, utilizing appropriate supportive care, for as long as possible.

Sincerely,

Hodley Hall

H.D. Hall
Executive Director

Enclosure

*We want to
help in every
way we can.*

ospice



of san francisco

MEMORANDUM

TO: Hospice Program Committee
Other Interested Parties

FROM: Norma Satten

RE: Summary of AIDS Home Care Unit Proposal

DATE: June 1, 1984

Enclosed is a summary of the proposal to the City of San Francisco for funding an AIDS Home Care and Hospice Unit. The summary also outlines the problems experienced in the previous fee-for-service arrangements, as well as the advantages of the proposed arrangements to fund positions and expenses for providing services.

VNA OF SAN FRANCISCO
SUMMARY

Proposal to the City of San Francisco
for the Establishment
of an AIDS Home Care and Hospice Unit

Early in 1983 the Visiting Nurse Association of San Francisco, San Francisco Home Health Service and Hospice of San Francisco began to provide skilled home health care and hospice care to patients with AIDS. In response to requests from the Board of Supervisors regarding the provision of needed services to AIDS patients, the three agencies jointly submitted a proposal to the City in concert with Coming Home. As a result, a contract with the City was arranged in September of 1983 which would pay for unreimbursed home care and hospice services to AIDS patients.

Several problems arose as we began to provide services under this contract. A major concern was the fee-for-service method of reimbursement which caused major cash flow problems. In addition, the rate of reimbursement under the fee-for-service contract was far below the cost of care and outstripped the various agencies' ability to subsidize care. Attendant care, which was an important ingredient in keeping people at home, also required the agency to front the money and caused a cash flow drain. Another problem relating to attendant care was the time required to recruit, train, supervise and schedule attendants. Hospice hired a social worker in April 1984, to carry out these duties, using monies received through a contract with the Shanti Project. Since the people residing in the Shanti Residence Project have used attendant care from our contract to a great extent, this was seen as an important joint effort.

A further problem for the City and for the patients was the fact that care was split between the home care division of the agency and the hospice care division of the agency. This made it difficult for the City to know which agency it was dealing with. It also caused difficulties for patients, since they had to deal with different staff and volunteers as they progressed through several levels of care.

To solve some of these problems, it has been proposed that an AIDS Home Care Unit be established within VNA of San Francisco. This unit will be responsible for providing both home care and hospice care for patients with AIDS. The City has been asked to finance the cost of the actual team of nurses, social workers, home health aides, attendants and others who are needed to carry out the work of this unit. Overhead costs are included in this program budget. The proposal indicates to the City that VNA of San Francisco will be responsible for collecting Medicare, Medi-Cal and private insurance reimbursement, and would remit these funds to the City as collected. The advantages of this arrangement are outlined on the attached page.

Two budgets have been prepared. One budget is a minimum budget, which will care for a caseload of approximately 18 patients at any one time. This unit is the smallest unit which can be organized and run economically. The net cost to the City for this budget is \$311,000, and would cost approximately \$3,500 per case. The second budget provides care for a daily caseload of between 30 and 36 patients, or a total of about 175 patients for the year. The net cost to the City for that budget is \$451,000, and the average net cost per case to the Health Department under the second budget is \$2,500. This is a considerable saving over hospitalization, which

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can cost up to \$1,000 per day.

The Health Department has allocated \$130,000 for the program in its present budget proposal to the Board of Supervisors. The AIDS Activity Office suggests that they will ask for a supplementary budget on July 1, 1984, to augment the amounts in the present budget.

Norma Satten
5/31/84

APPENDIXADVANTAGES OF ORGANIZING AND FUNDING A SEPARATE AIDS HOME CARE UNIT

- The staff and volunteers of the special AIDS unit would be specially trained and selected. They would be sensitive to the special needs and lifestyles of AIDS patients, knowledgeable about the treatment and progression of the disease, and understanding of the dynamics between the patient and family and friends.
- The patients would be dealing with the same staff and volunteers as they progressed through several levels of care:
 - (1) attendant care/custodial care for those who need assistance with activities of daily living (ADL's) and have no family members available;
 - (2) intermittent nursing and other professional services at home;
 - (3) intensive home care as the patient becomes more debilitated and/or disoriented;
 - (4) hospice care as the illness becomes terminal.
- There would be an integrated program of home care providing medical supervision, social, psychological, spiritual and practical support to the patient, his family and friends with patient care plans developed by a multi-disciplinary team of professionals and volunteers who meet weekly to monitor the progress of the patients. Care would be available 24 hours a day, 7 days a week. Support and bereavement counseling for families would also be provided.
- Attendant care would be organized more effectively with recruitment, training, supervision, support and scheduling under the supervision of the attendant care coordinator who would be part of the interdisciplinary team.
- There would be close coordination with San Francisco General Hospital through the satellite Hospice Program at SFGH, coordinated by the Coordinator of Hospice Services at SFGH and the liaison services of the intake nurse.
- There would be more effective coordination in providing attendant, home and hospice care services to residents at the Shanti Houses, since there would be only one unit with which to interact.

- There would be greater visibility for the home care program, thus increasing utilization of the home care services, and avoiding unnecessary institutionalization.
- An effective volunteer program would serve clients in the home, at SFGH, and at Garden Sullivan Hospital as a complement to Shanti volunteers and would reduce the need for attendant care.
- The alleviation of the cash flow and financial problems that arise from the fee for service mode as outlined above, since a monthly sum would be available to support the staff dedicated to providing care to AIDS patients.
- Affiliated groups such as Coming Home will relate to a more focused and identified home care program, which will make it easier to recruit volunteers and staff and to raise funds for AIDS services.
- Although well established relationships with other health and social service provider organizations are already available to the entire agency to ensure that patients can count on a comprehensive and coordinated array of services, the identifiable program will make that process easier.
- Relationships with the Public Health Nursing Unit of the Department of Public Health will be enhanced.
- There will be greater ease of administration of funds for the City, and greater accountability.

HELEN K SCHIETINGER
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PROFESSIONAL EXPERIENCE

CONSULTANT

1990 to present

Design, implement and evaluate HIV programs and develop HIV policy related to the care of people with HIV infection and the prevention of HIV transmission. Some examples of assignments include:

HRSA National AIDS Education and Training Centers Program: Designed and implemented needs assessment regarding training needs of HIV care providers by conducting and analyzing the results of 80 key informant interviews in 5 cities (1994).

AIDS Action Council/Foundation:

Facilitated workshop discussions of experts and drafted policy documents on the following: TB and HIV; mandatory HIV names reporting; AIDS case definition; impact of health care reform on HIV categorical public health programs; protections for persons with HIV in managed care systems (1992-4).

Designed and implemented an evaluation of federally funded HIV prevention programming. Resulting report: Good Intentions: A Report on Federal AIDS Prevention Programs (1991).

Conducted key informant interviews and a series of focus groups and developed a policy document recommending changes in federal AIDS prevention programming: A Blueprint for Reforming AIDS Prevention Programs (1992-3).

National Association of People with AIDS: Designed, implemented and analyzed data from a survey of the needs of people with AIDS in the United States HIV in America (1992).

American Red Cross Society: Implemented a feasibility study regarding teaching home nursing care to HIV caregivers (1992).

Rwanda Red Cross Society: Developed, evaluated and provided technical assistance to a project to train Red Cross volunteers to teach families basic nursing care (1991-4).

Norwegian Red Cross Society: Conducted an evaluation of HIV-related programming of the Kenya Red Cross Society (1993).

International Federation of Red Cross and Red Crescent Societies: Provided technical assistance to 3 Red Cross Societies in Africa on replicating Rwanda Red Cross project to train Red Cross volunteers to teach families basic nursing care (1993).

GTZ/Cameroon: Facilitated a strategic planning workshop for district-level Cameroonian public health workers to develop HIV prevention programming (1992).

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Technical Officer, Health and Social Services 1988 - 1990
Global Programme on AIDS, World Health Organization
Geneva, Switzerland

Designed and implemented interventions to improve provision of care to people with HIV infection and AIDS; assessed components of national and regional AIDS plans related to care of people with HIV infection; liased with UN and nongovernmental organizations regarding health and social services for people with HIV infection and AIDS; designed AIDS modules for basic nursing education.

Director, AIDS Education and Training 1986 - 1988
California Nurses Association, San Francisco, California, USA

Implemented and managed program to train health providers as health facility AIDS trainers throughout California, including program and curriculum design, staff recruitment, hiring, training and supervision, and program evaluation.

Psychotherapist 1985 - 1988
San Francisco, California, USA

Consulted with individuals and families in a mental health clinic serving predominantly Asian American clients and in private practice.

Director, AIDS Residence Program 1983 - 1986
Shanti Project, San Francisco, California, USA

Developed structure, policies and procedures for first residential housing program for people with AIDS in the United States; trained and supervised staff in assessing and monitoring physical and psychosocial status of clients; developed active referral system to medical, social, substance abuse treatment, and legal services; worked with health department in development of home care and hospice services for people with AIDS.

Coordinator, Kaposi Sarcoma Clinic 1982 - 1983
University of California Medical Center
San Francisco, California, USA

Developed procedures and protocols for patient management and monitoring; assessed and referred patients for psychological and social services and ongoing health care; provided AIDS education in the community and to health providers in hospitals and health care agencies.

Nurse in outpatient, inpatient and community settings 1971 - 1981

HONORS

Community Service Award, Bay Area Physicians for Human Rights, 1984
 Community Service Award, Alice B Toklas Democratic Club, 1985
 AIDS Nursing Recognition Award, Nursing Transitions, 1987
 National AIDS Nursing Award, Assistant Secretary for Health, USA, 1988

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SPECIAL APPOINTMENTS

Co-chair, Second National AIDS Forum, Denver, CO, June, 1983
 Co-chair, Lesbian and Gay Caucus of Public Health Workers, 1983-84
 AIDS Advisory Committee, National Institute of Mental Health, 1985
 Scientific Advisory Committee, American Foundation for AIDS Research, 1986 through 1991
 AIDS Outreach Advisory Committee, National Institute of Allergies and Infectious Diseases, 1986
 AIDS Health Services Advisory Committee, San Francisco Department of Public Health, 1986 to 1988
 AIDS Task Force, Div of Nursing, National Institutes of Health, 1987
 Oversight Committee, AIDS Public Education, American Red Cross, 1987-88
 Co-chair, Policy and Administration Track, National HIV/AIDS Update Conference, 1993 and 1994

EDUCATION	Degree	Year
Oberlin College, Oberlin, Ohio	B.A. Anthropology	1971
Dekalb College, Clarkston, Georgia	Associate Degree Nursing	1973
Sonoma State University, Rohnert Park, California	M.A. Marriage and Family Counseling	1981

LICENSES

Registered Nurses Licenses: California, USA, #F 263620
 Washington, DC USA, #58416

Marriage, Family and Child Counseling License: California, USA, MS22690

MEMBERSHIPS

American Public Health Association
 Association of Nurses in AIDS Care
 International AIDS Society
 National Council for International Health

PUBLICATIONS

AIDS Action Foundation. (March 1993) Should HIV Test Results be Reportable? A Discussion of Key Policy Questions. Washington DC: Author.

California Nurses Association. (1986) AIDS Education and Training Project: A Program Guide for Trainers. San Francisco: Author.

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- Schietinger, H. (1991) Curriculum for Training Red Cross Volunteers to Teach Families to Care for People with Chronic Illness and AIDS. Kigali Rwanda: Rwanda Red Cross.
- Schietinger, H. (1991) Good Intentions: A Report on Federal AIDS Prevention Programs. Washington DC: AIDS Action Council.

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Schietinger, H. (1992) "Personal and Community Coping with AIDS." AIDS and Society: International Research and Policy Bulletin 3(2): 4-12.

Schietinger, H. (1992) Project to Train Volunteers to Teach Families to Care for People with Chronic Illness, including AIDS, at Home: Evaluation Report. Kigali, Rwanda: Rwanda Red Cross Project Info-SIDA.

Schietinger, H. (1992) Tuberculosis and HIV Public Health Policy: A Dual Challenge. Washington DC: AIDS Action Foundation.

Schietinger, H, Almedal, C, Bizimungu, M, Karakezi J, & Ravn, B. (1993) "Teaching Rwandan families to care for people with AIDS at home." The Hospice Journal 9(1):33-53.

Schietinger, H & Lawrence, B. (June 1992) "Access to health care: We have a right to live and die with dignity." AIDS Action 17:5.

Schietinger, H & Levi, J (1993) A Blueprint for Reforming Federal AIDS Prevention Programs. Washington DC: AIDS Action Foundation.

Schietinger, H, & Lusby, G. (1983) "Infection Precautions for People with AIDS Living at Home." San Francisco: San Francisco AIDS Foundation.

Schietinger, H, & McCarthy, P. (1988) "Staff Education: Nurses and Others." In A Lewis (Ed). Nursing Care of the Patient with AIDS Rockville MD: Aspen Publications.

Schietinger, H, McCarthy, P, & Gillen, M. (December 1988) "A Strategy for Educating Health Care Providers about AIDS." Nursing Clinics of North America.

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October 8, 1981

TO: Hiro Tokubo
Clinic Administration
A-102

FROM: Marcus A. Conant, M.D. *Ma*

RE: NURSE COORDINATOR - KAPOSI'S SARCOMA CLINIC

In the past year, a new and highly aggressive form of Kaposi's Sarcoma has been seen in young homosexual men. There are now about 60 of these cases. 20% of the cases have died. Most of the cases have been found in New York, San Francisco, Los Angeles, and Atlanta. To date, we have about 20 cases in the San Francisco Bay Area, and we are currently following seven of these cases at this facility. If the current trend continues, we would anticipate seeing two or three new cases each month for the foreseeable future.

As I mentioned in our phone call last week, Dr. William Epstein has graciously given us space and staff support to establish a Kaposi's Sarcoma Clinic in the Dermatology area. The Clinic will meet on Thursday mornings from 9 until 12. Cases will be evaluated by the residents and professorial staff and if the diagnosis of Kaposi's Sarcoma is made, an involved protocol of laboratory studies including virology studies, immunology studies, genetics studies, histological studies, radiological studies, gastroenterological studies, ophthalmological studies and otolaryngological studies will be performed.

These studies cannot all be done on the UC Campus and specimens will have to be collected and routed to a variety of locations including, but not limited to, the Center for Disease Control in Atlanta, the Virology Laboratory in Berkeley, the Virology Laboratory at Letterman General Hospital, the Virology Laboratory at Mt. Zion Hospital. This data will have to be calculated and tabulated on a flow sheet so that meaningful comparisons between patients can be made.

Follow-up on patients will have to be coordinated to get them back at appropriate intervals to assess their response to therapy and to do repeat studies of the same nature as outlined above.

Hiro Tokubo
Clinic Administration
A-102
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We would like to recruit for a nurse coordinator who can perform these studies noted above and coordinate their implementation and collate the results for us. The individual should have completed nursing training so that he or she can draw blood and do patient interviews. The individual must be able to take medical history, and should be comfortable in working with homosexual patients. An individual familiar with the gay life style in San Francisco would be preferable for this position. The individual should be able to type at a modest rate and must have some form of transportation to move specimens around San Francisco.

As I indicated to you on the phone, we have an indication that we can get priority funds for this position. I would appreciate a breakdown from you on how much we should fund for this position, and how soon we can begin to recruit.

MAC/bjm
cc: Dr. John Ziegler, V.A.

Summer 1982

¹⁹⁵
Presentation by Helen Schieffinger
to the Nat'l Lesbian/Gay Health Conference

John L. Ziegler papers, AIDS History Project Archives,
Special Collections, UCSF Library

Thank you. It's good to be here. Before we begin, I'd like to find out a

little about your personal experience with these diseases.

--How many of you feel your life has been ^a affected by your awareness of
of the existence of this problem?

--How many know someone with KS or AIDS?

--How many know someone who has died?

--How many have worked in a health care setting with patients?

Thank you.

There is a lot I could share with you about the KS clinic at UCSF and about
my experiences coordinating the clinic and working with patients. In the allotted
time I've decided to first give you a brief description of the clinic, and then I'll
go into some of the issues which arise for the patient and the gay community. Last,
I want to mention the problems of labelling this a gay cancer.

Our KS clinic has four basic purposes.

1. To treat patients with KS.
2. To do research about the disease.
3. To educate the medical and lay communities.
4. To provide an emotional support system for the patients with this
devastating and frightening disease.

Ziegler
f: AIDS-publicity

The clinic is composed of a multidisciplinary team which meets on a regular
basis to review patient status and discuss current research developments. The team
includes a dermatologist, an oncologist, a gastroenterologist, a doctor of oral
medicine, an immunologist, a virologist, a host of other scientists of various
relevant specialities, a psychologist, and me. I attempt to coordinate all these

individuals into a cohesive unit for optimum^u patient care as well as efficient research. I am the only paid staff member, and my position is funded through a grant from the ACS.

As you know, the use of a team approach invites the separation of the patient into parts and systems, with each specialist attending to his or her own discipline. Unfortunately, this disease affects a variety of systems. In order to coordinate care of the patient, primary contact is maintained with the dermatologist, the oncologist and me. Other specialists serve as consultants when needed.

We only see patients who have already been diagnosed with KS. Our histopathologist re-reads the path slide of every referred case for a definitive diagnosis. We have found that this second opinion is critical because of the possibility of a presumptive diagnosis of KS in the gay man with a skin lesion. The histological changes can be subtle, and on at least 2 occasions the diagnosis has been reversed from positive to negative. The protocol for the initial staging workup includes extensive testing to determine the extent of disease, as well as immunological and virological studies.

Chemotherapy and radiation therapy have traditionally been standard treatment for KS. Radiation has been found to depress the immune system for up to one year after treatment ends. Therefore, we elect to use chemotherapy, the immunosuppressive effect of which begins to reverse when treatment is ended.

At present, we are following 24 patients. Seven of these are older men and one is an older Black woman all of whom have the traditional form of KS. Their disease is indolent and requires no treatment at this time. The other 17 patients are gay men between the ages of 22 and 46 whose^e immune systems are

characteristically deficient.

Our treatment protocol has 3 levels based on the extent of the disease.

--First, if the initial lesion was excised at the time of biopsy, and the patient is found to have no further evidence of disease at staging, he is simply monitored closely for any return of KS lesions. At the present time we have 3 patients in this category.

--Second, a patient who presents with localized lesions is treated with single agent chemotherapy, Velban. One of our patients on this therapy is in total remission and his course of therapy has been terminated. He is, of course, still being monitored closely. Of the last 4 patients begun on Velban, all have had either no further progression of their lesions or the lesions have diminished in size.

--Third, in the patient whose disease has progressed from the original site, we treat with three chemotherapeutic drugs. The success of treatment here seems related to how extensive the disease is.

Most of our current patients have been diagnosed in the early stages of disease, and are receiving outpatient treatment as they go about their daily lives. However, there is no way to know what will happen to these patients 12 months from now. In San Francisco there have been at least 6 deaths since January, 3 of whom were KS patients. We can only hope that diagnosing and treating the disease in its early stages will give the current patients a good prognosis.

The basic problem is that we do not know how to treat the underlying immunological deficiency. Superimposed on that problem is the fact that in treating-- using chemotherapy for treatment we cause further immunosuppression and therefore exacerbate the problem. In caring for patients we see not only the

devastating effects of the cancer itself, but also the opportunistic infections that attack these patients.^c We really feel caught^a in a catch-22 situation. In the two most recent deaths at UC, one patient had organ involvement with KS, but actually succumbed to pneumocystis, an opportunistic infection, ^{while} ~~and~~ the other experienced opportunistic infection, but succumbed to the cancer itself.

Needless to say, we are watching for any alternative therapy which begins to seem more effective than what we are now using. Interferon is the most potentially exciting, because of the presumption^h that it is an antiviral agent. It is being used with some KS patients in other settings, but it is far too early to know its effectiveness.

Now to get into some of the critical issues, some of which are the same ones which come up for anyone who has been diagnosed with cancer. Each individual has his own way of coping with the sudden onset of a catastrophic illness. Some of our patients have availed themselves of the services of the psychologist, some have received a tremendous amount of benefit from the support group provided by Shanti, an organization which deals with death and dying. Some patients reach out to their lovers, families, or friends for support. Others want no assistance on an emotional level, and may throw themselves into their work in order to not let the cancer get the best of them. As long as a person is able to maintain his prior level of functioning even this last way of coping may be effective.

~~But, if we have support, we need it. The person who denies the need for support is a person who is in a very difficult position.~~

~~people, as well as the other patients who have been treated, and the staff.~~ My strategy for dealing with individuals who deny the need for emotional support is to address these needs indirectly during the interactions that occur in direct patient care and contact. I try to be sensitive to their experience and provide an open

accepting environment where a variety of coping styles are supported. Usually more support is needed if the person deteriorates physically.

The diagnosis of cancer brings with it the shock of having a debilitating, disfiguring, and potentially fatal illness. As the disease progresses, the possibility of having KS lesions that show comes up: not being able to wear a bathing suit, having to wear long sleeves, or having dark spots on the face. Loss of hair ^{may result} from the treatments themselves. Tremendous changes in body image must be adjusted to. Progressive weakness with loss of Independence requires changes in self image. The loss of job may be devastating financially as well as emotionally.

Many issues that come up are specific to the fact that out patients are gay. For the person who has not come out to his family, to tell them he has a disease that has been popularly labeled a "gay disease" may seem impossible. Others have found it imperative. I remember one patient in icu on a ventilator, unable to speak, coming out to his mother, using a chalk board, before he died.

The person who has already come out to his family often is estranged and thus does not have the usual family support system in this time of crisis.

We have had a family become involved with their son in a concerned way, but then attempt to prevent the hospitalized patient's lover from seeing him. The absence of legally binding ties for homosexual relationships creates obvious difficulties for the lover of the patient. These can add to the heartbreak of the death of the patient. We had a case in which the patient's family insisted that the patient's lifestyle, and the grief of his significant other, not be acknowledged in the memorial service. If the person leaves no will, the loved one may lose access not only to the estate, but to precious personal belongings of the patient.

I talk about these things because they are unique to the gay patient, and become critical to be aware of in dealing with this potentially fatal illness.

The institutional homophobia which Jinny dealt with yesterday directly affects both the gay patient and the gay health care provider. The KS patient is labeled on the basis of his diagnosis, and has thus lost the option of being in the closet. Every care provider he comes in contact with knows who he is and has a stereotype about him. The gay health care provider may be incredibly threatened. The gay patient forces him to be confronted with the homophobia of the institution as well as his or her fear of personal disclosure if not out.

A critical issue arises in the possible factor of transmissibility. At present we tell our patients that indiscriminate sexual contact may make them vulnerable to sexually transmitted diseases. We also say that medical authorities think that in sexual activity they perhaps risk spreading a virus to their partner which may have caused their illness. We suggest the use of condoms, or forms of sexual activity that do not involve the transmission of semen, if the person decides to continue his sexual activity. This a highly charged area of concern, and even the suggestions themselves must be tempered with the awareness that we do not know the full answers at this time.

Some patients are so focused on dealing with their disease that ceasing sexual activity is no problem. Others already have a monogamous partner and simply continue that one sexual contact. We are monitoring these ongoing partners of patients. Others use sexual activity as a means of relieving stress and anxiety, and either have difficulty stopping or choose not to stop, having sexual activity.

But as health care providers, one of our major concerns is that these patients receive assistance in dealing with the factor of possible transmissibility in a manner that counteracts any guilt the patient may have about being gay. Internalized guilt creates the interpretation that the patient is being punished for homosexual activity, and this must be counteracted by those of us who are in a position to do so.

In terms of dealing with transmissibility, care must be taken that the community at large and health care providers not treat these individuals as if they have the plague.

This brings us to the fact that this is a crisis in the gay community at large. Two major needs arise which must be dealt with. One is a need for information, and the other is a need for adequate screening by the medical community. As you are aware, a tremendous amount of fear has been generated by these diseases. The community needs accurate information in order to be able to respond to the crisis intelligently rather than out of panic and fear. Individuals and health care professionals in SF have soaked up information like a sponge. Every day a member of the study group is giving a talk somewhere in the Bay Area about KS. We all have our slide presentations ready at a moment's notice. Every day I receive phone calls from gay men who want to know what to do because they noticed a spot on their skin, or think they may be immunodeficient. (Let me say that the majority of people who have been screened that I am aware of have not

8

and

had KS, are are treated for a simple skin problem.

The second community need, then is adequate screening. This requires an informed medical community. Any health care provider who makes contact with gay patients who enter the health care system for whatever reason should be particularly aware of asking about symptoms such as spontaneous spots on the skin, unexplained shortness of breath or dry cough, FUO's, chronic, unresolved flu symptoms, and chronically swollen LN's.

So far I have specified the gay patient and the implications of these diseases for the gay community and the gay health professional. This brings me to my last point.

To label this as the "gay cancer" or the "gay related immunodeficiency diseases" implies to the general homophobic public that gayness causes disease. It is critical to remain aware that although this is a disease prevalent in the gay community as opposed to in the straight community, that it is not caused by being gay. Certain aspects of certain gay people's lifestyle may be risk factors, or it may be that certain viruses or other pathogens are at this time residing primarily in gay men's bodies.

But any link between homosexuality per se, which has been around for as long as humankind, and disease, is made through irrational prejudice, not logic.

There is a delicate balance. On one side is the importance of educating the gay community about the risk factors of particular lifestyle practices, as well as providing the support systems within the community to assist individuals in coping with this devastating disease syndrome. On the side of the balance is the importance of realizing that this syndrome has been seen in heterosexual individuals, and that it is not a "gay disease." Germs do not discriminate on the basis of sexual preference. Labeling the diseases gay-related leaves them easy prey for the moral majority. It also precludes the possibility of having major federal funding for intensive research, particularly in an election year. *As far as I know, my position is the only one in the country specifically funded to facilitate research.*

9

Cultural homophobia runs deep and touches us all. It is often our personal feelings that are hardest to look at. I go back and forth between feeling secure in taking normal secretion precautions with the patients I deal with, and being very fearful of coming in contact with whatever the deadly thing is that has compromised the patients' immune system. The fear is of the unknown, and becomes amplified ~~in health~~ to the point that it manifests in irrational behavior that isolates the patient in senseless ways.

At UC, gay staff members, male or female, seem to experience feelings of ambivalence toward the patients ~~in~~^{the} hospital. They want to be, and are, very supportive to our gay brothers. But they also seem to react more strongly than the straight staff in fear of catching what the patient has. Of course there is a level of reasonable fear based on the possibility of transmission. There is also the identification with lifestyle risk factors that have been highlighted. But also, underneath that level is the level of internalized homophobia. The primitive gut reaction that grows out of our own homophobia is that we may catch this because we are gay and we too might be ^{punished} for our dirty lifestyle. We all who have come to this conference are on a conscious level gay and proud, and work hard to maintain this awareness. But I think we all carry in us the vestiges of the terrible wound inflicted on us by our society's attitudes toward homosexuality. As we deal with KS and AIDS, ~~xxxx~~ we must ~~xxxxxxxxxxx~~ be aware of all the levels on which we are affected.

Thank you.



SHANTI PROJECT

890 Hayes Street • San Francisco, California 94117 • 558-9644

Volunteer Counseling for Persons Facing Life-Threatening Illness and Bereavement

MARCH 1983

INFORMATION FOR GAY MALE AIDS PATIENTS

COMMON PROBLEMS, LIFESTYLE ISSUES,

AND RESOURCES

Helen Schietinger, MA, RN

Shanti Project AIDS Residences Director

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 - B. Sexuality and Sexual Activity
 - C. Factors Which May Help the Body's Immune System and Overall Health

I. COMMON PROBLEMS AND RESOURCES FOR COPING

A. Common Issues Which You May Face

1. Need for Information

- physicians have limited time to answer your questions
- there is limited medical knowledge about this new disease; much is not known, or is speculative or contradictory
- press coverage has often been sensationalist and inaccurate

2. Dealing with the Misinformation Which You and Others May Have and with Common Reactions To It

Myths and Stereotypes: (these are based primarily on media information and community "gossip")

- "It's a 'Gay Plague', 'Gay Cancer', etc."
- "Everyone who has it is very sexually active and uses a lot of drugs, especially poppers."
- "You can catch it by being around a patient."
- "It's always fatal."

Reactions Experienced by Many AIDS Patients:

- guilt about being gay
- guilt about having been or currently being sexually active
- shame and/or fear of telling friends and/or family
- not wanting to associate with other patients or other gay men
- feeling like a "leper"

Reactions of Others Will Vary:

- some are supportive and want to help in any way they can
- some avoid patients, even those who are close friends
- some stereotype patients in order to feel different from them, and therefore feel safe

Facts: Homosexuality does not cause disease; germs cause disease

- To date, 75% of the AIDS patients are gay men.
- These men cover a range from very sexually active to practically celibate, and their use of drugs ranges from none to a lot.
- AIDS is thought to be caused by an infectious agent, such as a virus which is spread by blood or body secretions shared in intimate (sexual) contact. People do not share body secretions simply by being around one another. (Refer to section II).
- There are AIDS patients who have died, but also AIDS patients who are working and continuing their lives as they did before they were diagnosed. Talking to other patients can be very helpful in understanding the range of degrees of the illness.

3. Deciding When To Tell Others and What To Tell Them

- Family
- Former and current sexual partners
- Friends
- Employers and fellow workers
- Roommates

You may find it helpful to talk to other AIDS patients or to a health care provider. Also, the information in this booklet will answer some of your questions.

4. Protecting Your Privacy, Either as a Gay Male or as an AIDS Patient

- you have a right to expect your identity and information on your case to be kept confidential unless you choose to go "public".
- if you find this information has been made public, talk with your health care provider and/or the KS Foundation.

5. Coping with and Exploring Your Emotional Reactions and Changes in Self-Image Associated with Being Sick

- some of your feelings may include anger, fear of loss of control and/or independence, fear of dying, or fear of the unknown.
- you may find yourself dealing with and grieving for loss of old habits, familiar sexual patterns, etc.

6. Dealing with a Maze of Various Doctors and Specialists (i.e., the Medical Establishment). Bring a friend to your doctor's appointment or to your tests to help you:

- ask questions
- speak up
- listen, and sort it all out later.

7. Handling Changes in Your Financial Situation

- major medical expenses, especially if you do not have or if you have lost your medical insurance
- possibly loss of employment
- possibly extra travel and/or housing expenses

Financial problems can be a new and very difficult burden. Refer to the resources under "B" to find help in areas such as housing, medical coverage, applying for disability, etc.

8. Getting One's Affairs in Order

Today, any adult should have a written will, particularly if she/he is gay. Many patients who had not done so before their diagnosis have decided to write a will now. Others have also chosen to appoint power of attorney to one of their close friends in the event they become unable to care for themselves. This is especially important if you are estranged from your family. Your next-of-kin will assume legal responsibility for you if not otherwise stated. Those who have written a will and/or appointed a power of attorney have found that this enables them to relax and get on with living. (The Shanti Project can provide resources for writing a legal will without paying a lawyer). Others have found that they were under too much stress when they first were diagnosed, and decided to wait until later to deal with these issues.

B. Resources You May Find Useful

1. Information

- K.S. Foundation - 864-4376

- *patient and community information
- *assistance with referrals

-Medical Information Meeting

- *Wednesday, 3-4:00 pm
- *SF General Hospital AIDS Clinic, Ward 86, Family Practice Building, corner of 22nd and Potrero
- *This is a weekly presentation of medical information about AIDS by the doctors and nurses of the AIDS clinic at SFGH.

-K.S. Patient Forum

- *This is only for K.S. patients.
- *Monthly meetings at the K.S. Clinic for K.S. patients to talk about medical and related aspects of K.S. and AIDS. Held the second Thursday of each month at 11 am in the Dermatology Conference Room, 3rd floor, 400 Parnassus.

2. Assistance With Financial Issues

-Social Security Office General Information - 996-3000

Applying for disability can be difficult and complicated. Ask for help from your social worker. There will soon be other resources available to help you apply. Ask the K.S. Foundation about these.

-Social Workers: See next section

3. Personal Support Individually or in Groups. Also Support for Loved Ones and/or Family

- Shanti Project - 558-9644

*Individual counseling and support groups

*AIDS Residential Program

*Community Volunteer Program

*Help for:

- people who have been told they may have an AIDS illness and are waiting for test results.
- people who have been diagnosed with an AIDS illness
- family and loved ones of persons with AIDS
- people with chronic illness, including some symptoms of AIDS, who fear development of AIDS

*Jim Geary, Executive Director; Andrew Lewallen, Office Manager

- Brookes Linten, Social Worker for SFGH AIDS Clinic
821-6478 or 821-8436

- Social Workers at individual hospitals

- Operation Concern - 563-0202

- AIDS/KS Foundation - 864-4376

*List of therapists who are aware of the issues which people with AIDS face

- SF Health Department

*Support groups for people with AIDS

-Michael Lipp - 558-2507

-Jay Canada - 558-2551

4. Personal Support in a Crisis

-Suicide Prevention - SF: 221-1423

East Bay: 849-2212

Someone is available to talk 24 hours a day. A good resource if you want to talk about your feelings. They deal with many issues besides suicide and are familiar with AIDS.

-Mission Crisis Center - 558-2071

8 am to 11 pm - Ask for Kim Storch or Jim Tate

II. LIFESTYLE ISSUES

A. Is AIDS Contagious?

So far, no one has identified an organism which causes AIDS. Regardless, most medical experts believe that AIDS is caused by an infectious agent such as a virus.

It is clear by who has NOT gotten AIDS that the organism is probably not airborne. If it were spread through the air, straight people who are around gay AIDS patients would have gotten it too. So far, no medical personnel who work with AIDS patients, and no people who have been in the same workplace as a patient, have gotten AIDS unless they are in a risk category (i.e., unless they are gay men, IV drug abusers, etc.).

The people who have gotten AIDS, for the most part, fit into particular groups: homosexual men, IV drug abusers, Haitians, prisoners, sexual partners of IV drug abusers, hemophiliacs, babies born to mothers who abuse IV drugs, and a baby who had blood transfusions. Because of who has gotten AIDS, it is believed that AIDS is spread by blood and by body secretions shared in close, intimate (sexual) contact. Also, it is believed that carriers of the supposed virus may be able to spread the virus or other organism for long periods of time, up to 24 months. We assume that you came down with AIDS by having sexual contact with someone who was carrying the organism. That person may not have had any symptoms of AIDS.

You may still be carrying a virus or other organism which causes AIDS which may be spread by body secretions. Below is a list of body secretions and tips on how to be very careful not to spread them. The secretions may or may not be carrying the supposed AIDS organism, but it is better to be safe than sorry. Hopefully, these guidelines will enable you to relax about what is safe and will prevent unfortunate situations such as friends or roommates avoiding you.

1. Saliva - Sharing a bathroom with others is fine; sharing a toothbrush is not. It's probably not a good idea to share the same glass or silverware at the same time. But sharing a kitchen or sharing dishes which have been washed with soap and water after use should be perfectly safe. Principles of common sense hygiene should be enough to make living with others safe.
2. Mucus - When you blow your nose: a) discard the tissue in the toilet or in a paper bag or lined garbage can; b) wash your hands; and c) when coughing, cover your mouth with a tissue or handkerchief.
3. Urine - After urinating, wash your hands.
4. Feces - After a bowel movement, wash your hands. Be particularly careful if you have diarrhea, or if you are collecting a stool specimen.

5. Semen - After ejaculation: a) it is best to ejaculate into your hand or into a condom; b) make certain the semen is discarded in the sink; or in a tissue placed in the toilet, in a paper bag, or a lined garbage can; c) wash your hands; and d) see section on sexual activity for more information.
6. Blood and Wound Secretions - (cuts, scabs, sores, bloody nose or gums): a) when you take off a bandaid or dressing, discard the dressing in a plastic bag or lined garbage can; b) wash your hands; c) when getting dental work done, suggest that the hygienist or dentist wear gloves and tell them you have AIDS; and d) do not donate blood. NOTE: You need to be more careful with blood than any other body fluid.

So far, everything has been simple, common sense. Here's the last bit of logical information. For any secretion to affect another person, there must be a way for it to go from your body into theirs: there must be a point of entry. This could be in the mouth, mucous membrane of the nose, eyes or anus, or a cut in the skin. You can always wash secretions off of your hands, their hands, the counter top, etc. There is only one area in which keeping your body secretions out of other people is a real problem, and that is in the area of sexuality. That is why the subject has a whole section of its own.

B. Sexuality and Sexual Activity

Sexual orientation itself only causes problems because of society's values and negative judgements. Being homosexual can cause shame only because of what others say, and can cause guilt only because we grew up hearing that being gay was bad. There is nothing inherently wrong with homosexuality.

In and of itself, homosexual activity does not cause disease. There are many diseases, however, which can be spread from person to person in sexual activity. We assume that AIDS is probably one of them, and that you may be capable of transmitting AIDS during sexual activity in which body fluids are exchanged (semen, urine, saliva, feces, blood). Also, because you are immuno-compromised, you need to protect yourself from catching other sexually transmitted diseases which can be spread during sexual activity.

For most people, being sexual is a very important way of being close to others, of interacting with others, and of releasing tension. Many patients whose sex drive disappears in the crisis of first being sick, find that they again feel a need for sexual contact with others after 2 or 3 months.

What are your options?

*Refraining from sexual activity with other people. If you choose celibacy, you may need to continue or increase being intimate with other people in other ways (massage and hugging are two examples).

*Self-pleasuring. Masturbating is a good way of being sexual if you properly dispose of your semen (see previous section). This can involve videos, phone sex, books or jacking off with other people.

*If you decide to continue being sexual with others:

- a. You should tell your partner(s) you have a potentially transmissible illness -- AIDS. For some patients, this has resulted in being turned down. In many cases, however, it has led to close contact, a discussion about how to be sexual without sharing body secretions, and incredibly intimate sexual encounters. It is only fair to allow your partner to decide whether he feels comfortable being sexual with you. AIDS is not well-defined; and, though it is felt that avoiding the sharing of body fluids will minimize risk of transmission, it is not known for certain.
- b. Make sure your partners are disease-free and make sure that you don't expose yourself to intestinal parasites, hepatitis, herpes, CMV, etc.
 - 1) Don't ingest semen, by mouth or rectum, to avoid CMV.
 - 2) The best, probably only, way to avoid intestinal parasites is to avoid coming in direct contact with the mucous membrane of the rectum and intestinal tract, and with fecal material, and with anything which has been inside the rectum of a person who has amoebas. Because there is an epidemic of amoebas in the gay men's community, and because many people who have amoebas have no symptoms, it is safest to assume that anyone might have amoebas.
 - 3) Herpes lesions, syphilis chancres, and venereal warts are visible except inside the mouth or anus. Look for them on your partner. You can catch these diseases by direct contact with the lesion.
 - 4) Gonorrhea doesn't always show, although a bad case of the drip is pretty obvious.
- c. Discuss the limits of your sexual activity with your partner prior to engaging in sex so that each person can be responsible for making sure the limits are honored.
- d. Some suggestions for having sex in ways which do not expose your partner to your body fluids (for your safety, you probably should not expose yourself to your partner's body fluids either!):
 - *The active partner in rectal intercourse could wear a condom (not an inexpensive one which is more likely to break). When "pulling out", be sure to hold onto the condom.
 - *Avoid French kissing. Stick to ears, nipples, umbilicus, etc. Explore erogenous zones other than mouth and anus.

These are considerable restrictions, but many gay men are making changes in their sexual activities. Many are finding their new activities to be fun, satisfying, and increasingly intimate.

Above all, don't panic. AIDS and restricted sexual activity are not prison sentences. Live in a healthy way, and as fully as possible. Talk with other patients (Sex is a regular topic of conversation among AIDS patients) and other people.

C. Factors Which May Help the Body's Immune System and Overall Health

1. Nutrition

- Eat well-balanced meals to get enough protein, vitamins, minerals and calories.
- Take vitamins if your diet is inadequate.
- Special considerations: If you have any of the following, you have special nutritional requirements and need to talk with your physician and/or the nutritionist. Nutritionist at UC Medical Center: Kathy McHenry, RD, MS - 666-2291.

*Diarrhea - Causes depletion of potassium, and lack of absorption of important vitamins, minerals, and nutrients. If you have diarrhea that lasts more than 4 or 5 days, you should see your doctor.

*Weight Loss - Taxes your body's resources by making it tap into its own reserve of protein and nutrients. If you lose a lot of weight (10 lbs. or more), you have special nutritional needs.

*Lack of Appetite - Often chemotherapy, other medications, and simply being sick can cause you to lose your appetite. Ask a nurse or nutritionist for help if you have this problem. The single most important thing you can do for yourself right now is provide your body with excellent nutrition. Eating is critical.

*Recent Alcohol Abuse - Causes depletion of important vitamins, minerals, and nutrients. Multi-vitamins, especially B complex and minerals, should be taken for 3 months.

2. Proper Exercise and Rest

- Helping the body be healthy means getting enough sleep, often more than usual if the body is fighting infection. If you get tired, take a nap!
- Exercise is important for circulation, appetite, good muscle tone, and proper elimination. Amount of exercise will vary from person to person. If you were physically active before and feel good, continue your previous activities. If you are feeling exhausted much of the time, pick your best time of day and take a short walk, resting afterwards. Talk to your doctors about what's best for you.

3. Reducing Stress and Maintaining Emotional Well-Being

- It is known that severe stress can contribute to illness.
- Many things can be stressful, from not getting enough sleep and working long hours, to going on a vacation. Certainly being diagnosed with AIDS is stressful.
- There may be aspects of your daily life which you may decide are too stressful right now, and which you may want to change.

- There are also activities such as meditation and massage which you might choose to add to your life to help manage or reduce stress in this difficult time.
- SFGH Alternative Therapies Unit - 821-5139. This department offers a variety of activities, including acupuncture, acupressure, and biofeedback, to help the body relax and to enhance healing.
- Many people benefit from talking to someone when they are experiencing difficult times. There are many excellent counselors and therapists available in the community who are knowledgeable about the crisis of AIDS and its impact on patients. For example, there are resources or lists of therapists at the following places:
 - *Shanti Project - 558-9644
 - *Operation Concern - 563-0202
 - *Mission Crisis Center - 558-2071
 - *K.S. Foundation - 864-4376
 - *SFGH AIDS Clinic - 821-8830
 - *K.S. Clinic - 666-1407

4. Cutting Down on Alcohol and Drugs

- It is known that alcohol, marijuana, cocaine, and other recreational drugs take a toll on the body, and negatively affect the immune system.
- Alcohol and drugs blur your ability to make good decisions; and, when taken in excess, can contribute to your not taking care of yourself.
- Limited use of alcohol, meaning one to two drinks occasionally, is acceptable to some doctors (there is the same amount of alcohol in a glass of wine, bottle of beer, or shot of whiskey). However, individuals who have chronically abused alcohol or drugs should strongly consider stopping altogether.
- If you have difficulty cutting down on alcohol or drugs, don't hesitate to ask for help. This is not an easy time to quit using something that helps you relax temporarily. The overall effect of drugs/alcohol use is temporary relaxation followed by a long period of irritability.
- Getting high is a natural phenomenon which can be reached through alcohol and drugs, but also through relaxation, dance, music, sex, and other natural activities. You can learn to get high naturally.
- Resources
 - *Substance Abuse Services - 863-8111 - 18th Street Services
 - *Alcoholics Anonymous - 661-1828 - There are Gay AA meetings and centers in town.
 - *Narcotics Anonymous - 893-2686

5. Avoiding Sexually Transmitted As Well As Other Diseases

- Your immune system is not functioning properly; you should not expose yourself to infections, particularly sexually transmitted diseases (STD's).
- AIDS patients do not seem to be more susceptible than other people to common colds or bacterial infections. The immune deficiency of AIDS leaves you unprotected against fungal and yeast infections in particular and opportunistic infections such as pneumocystis pneumonia. Nevertheless, use common sense about exposing yourself to people who are ill with the flu, etc. There doesn't seem to be any reason for you to avoid public places.
- Avoid exposure to animal wastes. Wear rubber gloves when cleaning behind pets. If your cat or other pet appears to be sick, have it checked immediately. (You may be susceptible to some infections which animals carry).
- There are several very common STD's in the gay men's community, some of which may not cause symptoms in men who are spreading them. (Hepatitis B, amoebiasis, other intestinal parasites, CMV).
- Thus if you decide to continue to be sexual, you should be certain your partners are free of disease. Also limit the ways in which you are sexual.
- This means not having anonymous sex, and only being with people whom you know have been medically checked for hepatitis, intestinal parasites, gonorrhea and syphilis, and who have no herpes lesions or venereal warts. Please be sure to read one of the several brochures about healthy gay male sex, available through the K.S. Foundation or the K.S. Clinic ("Play Fair": "Guidelines and Recommendations for Healthy Gay Sex Activity"). Also, refer to Section B.



HOSPITALS AND CLINICS

SAN FRANCISCO, CALIFORNIA 94143

Robert K. Bolan, private collection

March 1983

INFORMATION FOR GAY MALE AIDS PATIENTS:COMMON PROBLEMS, LIFESTYLE ISSUES,AND RESOURCES

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and

AIDS Clinic, SF General Hospital

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 - C. Factors Which May Help the Body's Immune System and Overall Health

I. COMMON PROBLEMS AND RESOURCES FOR COPING

A. Common Issues Which You May Face

1. Need for Information

- physicians have limited time to answer your questions
- there is limited medical knowledge about this new disease; much is not known, or is speculative or contradictory
- press coverage has often been sensationalist and inaccurate

2. Dealing with the Misinformation Which You and Others May Have and with Common Reactions To It

Myths and Stereotypes: (these are based primarily on media information and community "gossip")

- "It's a 'Gay Plague', 'Gay Cancer', etc."
- "Everyone who has it is very sexually active and uses a lot of drugs, especially poppers."
- "You can catch it by being around a patient."
- "It's always fatal."

Reactions Experienced by Many AIDS Patients:

- guilt about being gay
- guilt about having been or currently being sexually active
- shame and/or fear of telling friends and/or family
- not wanting to associate with other patients or other gay men
- feeling like a "leper"

Reactions of Others Will Vary:

- some are supportive and want to help in any way they can
- some avoid patients, even those who are close friends
- some stereotype patients in order to feel different from them, and therefore feel safe

Facts: Homosexuality does not cause disease; germs cause disease

- To date, 75% of the AIDS patients are gay men.
- These men cover a range from very sexually active to practically celibate, and their use of drugs ranges from none to a lot.
- AIDS is thought to be caused by an infectious agent, such as a virus which is spread by blood or body secretions shared in intimate (sexual) contact. People do not share body secretions simply by being around one another. (Refer to section II).
- There are AIDS patients who have died, but also AIDS patients who are working and continuing their lives as they did before they were diagnosed. Talking to other patients can be very helpful in understanding the range of degrees of the illness.

3. Deciding When To Tell Others and What To Tell Them

- Family
- Former and current sexual partners
- Friends
- Employers and fellow workers
- Roommates

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- you have a right to expect your identity and information on your case to be kept confidential unless you choose to go "public".
- if you find this information has been made public, talk with your health care provider and/or the KS Foundation.

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- some of your feelings may include anger, fear of loss of control and/or independence, fear of dying, or fear of the unknown.
- you may find yourself dealing with and grieving for loss of old habits, familiar sexual patterns, etc.

6. Dealing with a Maze of Various Doctors and Specialists (i.e., the Medical Establishment). Bring a friend to your doctor's appointment or to your tests to help you:

- ask questions
- speak up
- listen, and sort it all out later.

7. Handling Changes in Your Financial Situation

- major medical expenses, especially if you do not have or if you have lost your medical insurance
- possibly loss of employment
- possibly extra travel and/or housing expenses

Financial problems can be a new and very difficult burden. Refer to the resources under "B" to find help in areas such as housing, medical coverage, applying for disability, etc.

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Today, any adult should have a written will, particularly if she/he is gay. Many patients who had not done so before their diagnosis have decided to write a will now. Others have also chosen to appoint power of attorney to one of their close friends in the event they become unable to care for themselves. This is especially important if you are estranged from your family. Your next-of-kin will assume legal responsibility for you if not otherwise stated. Those who have written a will and/or appointed a power of attorney have found that this enables them to relax and get on with living. (The Shanti Project can provide resources for writing a legal will without paying a lawyer). Others have found that they were under too much stress when they first were diagnosed, and decided to wait until later to deal with these issues.

B. Resources You May Find Useful

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- *assistance with referrals

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Applying for disability can be difficult and complicated. Ask for help from your social worker. There will soon be other resources available to help you apply. Ask the K.S. Foundation about these.

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-people who have been told they may have an AIDS illness and are waiting for test results

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*List of therapists who are aware of the issues which AIDS patients face

-S.F. Health Department

*Support groups for AIDS patients

-Michael Lipp - 558-2507

-Jay Canada - 558-2551

This meeting is on Tuesday nights at Health Center I.

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Someone is available to talk twenty-four hours a day. A good resource if you want to talk about your feelings. They deal with many issues besides suicide, and are familiar with AIDS.

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8 am to 11 pm - Ask for Kim Storch or Jim Tate

II. LIFESTYLE ISSUES

A. Is AIDS Contagious?

So far, no one has identified an organism which causes AIDS. Regardless, most medical experts believe that AIDS is caused by an infectious agent such as a virus.

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You may still be carrying a virus or other organism which causes AIDS which may be spread by body secretions. Below is a list of body secretions and tips on how to be very careful not to spread them. The secretions may or may not be carrying the supposed AIDS organism, but it is better to be safe than sorry. Hopefully, these guidelines will enable you to relax about what is safe and will prevent unfortunate situations such as friends or roommates avoiding you.

1. Saliva - Sharing a bathroom with others is fine; sharing a toothbrush is not. It's probably not a good idea to share the same glass or silverware at the same time. But sharing a kitchen or sharing dishes which have been washed with soap and water after use should be perfectly safe. Principles of common sense hygiene should be enough to make living with others safe.
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5. Semen - After ejaculation: a) it is best to ejaculate into your hand or into a condom; b) make certain the semen is discarded in the sink; or in a tissue placed in the toilet, in a paper bag, or a lined garbage can; c) wash your hands; and d) see section on sexual activity for more information.
6. Blood and Wound Secretions - (cuts, scabs, sores, bloody nose or gums): a) when you take off a bandaid or dressing, discard the dressing in a plastic bag or lined garbage can; b) wash your hands; c) when getting dental work done, suggest that the hygienist or dentist wear gloves and tell them you have AIDS; and d) do not donate blood. NOTE: You need to be more careful with blood than any other body fluid.

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Sexual orientation itself only causes problems because of society's values and negative judgements. Being homosexual can cause shame only because of what others say, and can cause guilt only because we grew up hearing that being gay was bad. There is nothing inherently wrong with homosexuality.

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For most people, being sexual is a very important way of being close to others, of interacting with others, and of releasing tension. Many patients whose sex drive disappears in the crisis of first being sick, find that they again feel a need for sexual contact with others after 2 or 3 months.

What are your options?

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*Self-pleasuring. Masturbating is a good way of being sexual if you properly dispose of your semen (see previous section). This can involve videos, phone sex, books or jacking off with other people.

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- a. You should tell your partner(s) you have a potentially transmissible illness -- AIDS. For some patients, this has resulted in being turned down. In many cases, however, it has led to close contact, a discussion about how to be sexual without sharing body secretions, and incredibly intimate sexual encounters. It is only fair to allow your partner to decide whether he feels comfortable being sexual with you. AIDS is not well-defined; and, though it is felt that avoiding the sharing of body fluids will minimize risk of transmission, it is not known for certain.
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- d. Some suggestions for having sex in ways which do not expose your partner to your body fluids (for your safety, you probably should not expose yourself to your partner's body fluids either):

*The active partner in rectal intercourse could wear a condom (not an inexpensive one which is more likely to break). When "pulling out", be sure to hold onto the condom.

*Avoid French kissing. Stick to ears, nipples, umbilicus, etc.
Explore erogenous zones other than mouth and anus.

These are considerable restrictions, but many gay men are making changes in their sexual activities. Many are finding their new activities to be fun, satisfying, and increasingly intimate.

Above all, don't panic. AIDS and restricted sexual activity are not prison sentences. Live in a healthy way, and as fully as possible. Talk with other patients (Sex is a regular topic of conversation among AIDS patients) and other people.

C. Factors Which May Help the Body's Immune System and Overall Health

1. Nutrition

- Eat well-balanced meals to get enough protein, vitamins, minerals and calories.
- Take vitamins if your diet is inadequate.
- Special considerations: If you have any of the following, you have special nutritional requirements and need to talk with your physician and/or the nutritionist. Nutritionist at UC Medical Center: Kathy McHenry, RD, MS - 666-2291.

*Diarrhea - Causes depletion of potassium, and lack of absorption of important vitamins, minerals, and nutrients. If you have diarrhea that lasts more than 4 or 5 days, you should see your doctor.

*Weight Loss - Taxes your body's resources by making it tap into its own reserve of protein and nutrients. If you lose a lot of weight (10 lbs. or more), you have special nutritional needs.

*Lack of Appetite - Often chemotherapy, other medications, and simply being sick can cause you to lose your appetite. Ask a nurse or nutritionist for help if you have this problem. The single most important thing you can do for yourself right now is provide your body with excellent nutrition. Eating is critical.

*Recent Alcohol Abuse - Causes depletion of important vitamins, minerals, and nutrients. Multi-vitamins, especially B complex and minerals, should be taken for 3 months.

2. Proper Exercise and Rest

- Helping the body be healthy means getting enough sleep, often more than usual if the body is fighting infection. If you get tired, take a nap!
- Exercise is important for circulation, appetite, good muscle tone, and proper elimination. Amount of exercise will vary from person to person. If you were physically active before and feel good, continue your previous activities. If you are feeling exhausted much of the time, pick your best time of day and take a short walk, resting afterwards. Talk to your doctors about what's best for you.

3. Reducing Stress and Maintaining Emotional Well-Being

- It is known that severe stress can contribute to illness.
- Many things can be stressful, from not getting enough sleep and working long hours, to going on a vacation. Certainly being diagnosed with AIDS is stressful.
- There may be aspects of your daily life which you may decide are too stressful right now, and which you may want to change.

-There are also activities such as meditation and massage which you might choose to add to your life to help manage or reduce stress in this difficult time.

-SFGE Alternative Therapies Unit - 821-5139. This department offers a variety of activities, including acupuncture, acupressure, and biofeedback to help the body relax and to enhance healing.

-Many people benefit from talking to someone when they are experiencing difficult times. There are many excellent counselors and therapists available in the community who are knowledgeable about the crisis of AIDS and its impact on patients. For example, there are resources or lists of therapists at the following places:

- *Shanti Project - 558-9644
- *Operation Concern - 563-0202
- *Mission Crisis Center - 558-2071
- *K.S. Foundation - 864-4376
- *SFGE AIDS Clinic - 821-8830
- *K.S. Clinic - 666-1407

4. Cutting Down on Alcohol and Drugs

-It is known that alcohol, marijuana, cocaine, and other recreational drugs take a toll on the body, and negatively affect the immune system.

-Alcohol and drugs blur your ability to make good decisions; and, when taken in excess, can contribute to your not taking care of yourself.

-Limited use of alcohol, meaning one to two drinks occasionally, is acceptable to some doctors (there is the same amount of alcohol in a glass of wine, bottle of beer, or shot of whiskey). However, individuals who have chronically abused alcohol or drugs should strongly consider stopping altogether.

-If you have difficulty cutting down on alcohol or drugs, don't hesitate to ask for help. This is not an easy time to quit using something that helps you relax temporarily. The overall effect of drugs/alcohol use is temporary relaxation followed by a long period of irritability.

-Getting high is a natural phenomenon which can be reached through alcohol and drugs, but also through relaxation, dance, music, sex, and other natural activities. You can learn to get high naturally.

-Resources

- *Substance Abuse Services - 863-8111 - 18th Street Services
- *Alcoholics Anonymous - 661-1828 - There are Gay AA meetings and centers in town.
- *Narcotics Anonymous - 893-2686

5. Avoiding Sexually Transmitted As Well As Other Diseases

- Your immune system is not functioning properly; you should not expose yourself to infections, particularly sexually transmitted diseases (STD's).
- AIDS patients do not seem to be more susceptible than other people to common colds or bacterial infections. The immune deficiency of AIDS leaves you unprotected against fungal and yeast infections in particular and opportunistic infections such as pneumocystis pneumonia. Nevertheless, use common sense about exposing yourself to people who are ill with the flu, etc. There doesn't seem to be any reason for you to avoid public places.
- Avoid exposure to animal wastes. Wear rubber gloves when cleaning behind pets. If your cat or other pet appears to be sick, have it checked immediately. (You may be susceptible to some infections which animals carry).
- There are several very common STD's in the gay men's community, some of which may not cause symptoms in men who are spreading them. (Hepatitis B, amoebiasis, other intestinal parasites, CMV).
- Thus if you decide to continue to be sexual, you should be certain your partners are free of disease. Also limit the ways in which you are sexual.
- This means not having anonymous sex, and only being with people whom you know have been medically checked for hepatitis, intestinal parasites, gonorrhea and syphilis, and who have no herpes lesions or venereal warts. Please be sure to read one of the several brochures about healthy gay male sex, available through the K.S. Foundation or the K.S. Clinic ("Play Fair": "Guidelines and Recommendations for Healthy Gay Sex Activity"). Also, refer to Section B.

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COMING UP!

Largest Lesbian/Gay Circulation in the Bay Area

MARCH, 1983

What to Expect At the KS Clinic

Coming Up!, (March 1983)

by Michael Helquist

Remember when "going to the clinic" always meant the VD clinic for a check-up exam, or an in-and-out treatment for VD? Now there's more than one clinic to visit. For more and more men the trip to the clinic has meant going to the Kaposi's sarcoma (KS) clinic at UC San Francisco or the newly formed AIDS clinic at SF General Hospital.

KS Clinic co-directors Marcus Conant, MD, and Paul Volberding, MD, received funding from the American Cancer Society to establish a clinic at UCSF in December of 1981. When the clinic first got underway in January of 1982, twenty KS patients were being seen and treated. Now, a little more than a year later, 60-70 KS patients are being seen at the clinic.

Helen Schietinger, RN, began her position as Nurse Coordinator of the KS Clinic in January of 1982. Schietinger's background includes several years as a home health nurse in Marin County and as a rehabilitation nurse specialist. She has quickly taken a leadership role, locally and nationally, in the efforts to treat effectively and compassionately the many individuals who have contracted AIDS and KS. Schietinger is 34 years old. As a lesbian, she brings to her job special understanding of the effect this AIDS epidemic is having on the lesbian and gay community.

Helen, the KS Clinic is not a walk-in clinic. A person needs to be referred by a physician first. What is the procedure for this?

Anyone who comes to the KS Clinic will already have seen a doctor and will have gotten a biopsy that is positive for Kaposi's sarcoma. Then that person will be referred here. I make an appointment to see the person myself and talk to him about what to expect in the next few weeks. I explain that he will be "staged," which is a term that means getting lots of tests and blood work done to determine the extent of the illness. This process tells us exactly how advanced the cancer is. It also allows us to determine the immunological status of the person. The individual is also seen by a dermatologist, and receives a physical exam and has a medical history taken by an internist in the KS Clinic.

Once this initial "staging" is completed, the person speaks with the oncologist, Dr. Paul Volberding, who will recommend appropriate treatment based on the individual's test results. Treatment is



Photo by Kim Corisio

usually instituted in the oncology clinic at San Francisco General Hospital (SFGH). That's basically the initial process for someone who is referred to the KS Clinic.

If someone had many of the symptoms of AIDS without a positive biopsy for KS, he would not come here. Where would he go?

If individuals with symptoms of AIDS but without spots came to the UCSF system, they would be seen in the screening clinic on the first floor of the Ambulatory Care Clinic at 400 Parnassus, to determine whether they would need to be seen in a more specialized clinic for further tests. The city health department also has AIDS screening clinics, where the doctor decides if a person needs a further workup. If so, he would be referred to the AIDS clinic at SFGH. There he would be seen by the team that's assembled for that purpose. A private physician can also refer patients to the special AIDS clinic at SFGH which has a lot of experience dealing with AIDS patients.

For those again who have signs of KS a private physician would perform the biopsy?

Yes, a person with spots or lesions would see a private physician, or a physician at the dermatology clinic at UCSF could do it. There is also a dermatology clinic at SFGH where people without insurance or income can go. KS is the cancer that many people with AIDS have gotten. The signs of KS are purplish or reddish spots on the skin that don't itch or hurt. They can be flat or raised, and they may appear anywhere on the body, including in the mouth.

A number of people don't know what's specifically involved with the staging that you mention. They don't know what tests are going to be performed. There's some feeling that prior knowledge of some tests would be frightening—some people don't like needles, and there's that reason to be scared. At the same time, this lack of knowledge keeps this process pretty mysterious.

That's why I have a KS person come to me first. Originally, I found that if the person just came in to the clinic and started seeing doctors for the different tests, he didn't get a very complete picture of what was happening. I prefer to sit down with someone and answer as many questions as possible and give referrals to resources in the community for support. I make sure the person knows about the Shanti Project and other resources, so he doesn't have to go through this alone. I try to see that the person understands as much as possible what's going to happen. The worst part is not knowing. The more gaps of information we can fill in for a person the better. Even though a whole lot of people seem to be scared of knowing anything, I find that once the process is demystified and the tests are demystified, it's not quite as frightening.

Would you demystify that process now? Even those of us who have friends who have already gone through this have a pretty incomplete picture of what's involved. I've heard you referred to as Count Dracula for all the blood you take in the tests, but what else is involved?

OK. We know the patient has KS in one place or the body. We need to determine if there are any other spots or lesions. One of the tests is called endoscopy. In this case that means that a lighted tube is inserted through the mouth into the stomach to examine the lining of the stomach wall, the mucous membrane, to see if there are any KS lesions located there. A lighted tube is also inserted into the rectum for the other part of the endoscopy to examine the lining of the colon for lesions. This is done by Dr. David Altman, after medication is given to relax the patient.

If the patient has swollen lymph nodes, we will recommend a lymph node biopsy to see if there might be some tumor tissue there. The individual is also examined by a doctor of oral medicine, Dr. Frnacine Loxoda, who examines the entire inside of the mouth and the back of the throat for anything suspicious. She also examines the tongue to see if there might be a yeast infection which would need to be treated. In addition, she conducts a skin test, which is one way of determining the state of the immune system. A small amount of antigens are put under the surface of the skin on four different places on the arm. After two days the person comes back to her to see if the body has responded to the antigens. The presence or absence of a bump or reaction to the antigens indicates whether

to a foreign substance. We also want to look at the person's chest to catch any signs of pneumocystis pneumonia; so there's a chest x-ray. And we want to figure out how their pulmonary function is doing. The patient blows into a machine that tests different pulmonary functions. If there is anything abnormal about these test results, arterial blood will be taken from the wrist, and other tests will be scheduled.

Other than these tests and seeing the doctors for a history and a physical, you're right, everything else is blood work. And there's a lot of blood work to be done. We look at what infections the person might have or might have been exposed to in the past by looking at antibody titers, and we look specifically for the presence of hepatitis and cytomegalovirus (CMV). We also look at the immune system in other ways: through an examination of the red blood cells and the white blood cells. All of these things are needed to figure out just exactly what the state of the person's health is right now.

Does the individual need to be hospitalized for these tests?

No, all of these exams occur on an outpatient basis. An appointment is made; a patient goes to the doctor's office; each test or appointment may take 2 to 3 hours; and then the person returns home. It usually takes from 3 to 4 weeks to get all of the testing done.

All of these staging tests are needed to determine the condition of the patient? None of these are being performed for separate research work?

Right. In addition to what I've talked about so far, there is blood work I do for research, but only if the person agrees and has signed an informed consent and knows that I'm taking the blood for research purposes. If the patient is willing, there might be extra biopsies performed. Nobody has anything done to them for research without their consent.

Do you suggest that when a person first comes to the KS Clinic that he bring someone with him?

It depends on the person. For many people, that's very helpful. Others feel that they want to face this on their own. But if someone is feeling anxious and has a lot of questions and is feeling frightened, more than likely it would be helpful to have someone accompany him to remember what is said.

I also give the patient written information which explains these tests. Many people who receive a brand new diagnosis of any kind of serious illness become somewhat numb on some levels. They tend not to remember much of what's said during the medical appointment.

The process of being staged is very confusing because there's a lot involved. When people enroll at the KS Clinic, they become patients of several physicians, specialists, who are in consultation. Thus there isn't one single physician/patient relationship. I try to provide the patient with a focal point. Once the person has finished all the tests and has begun treatment, it gets much easier. Then the patient primarily goes to one location once a week or several times a week for treatment.

Not only those with recent diagnoses of AIDS but also their friends are forced to become medically sophisticated to varying degrees. All of sudden we're learning about these new illnesses and tests. And it is important to become educated about all this, especially if you're close to someone with AIDS. It's difficult for the person with AIDS to explain all these illnesses and tests from the beginning to each new person.

Yes, it is, and the other difficulty that many patients have is taking care of their friends who are freaking out over this diagnosis. I find this happening over and over.

One thing I would counsel friends is never to show a spot to a KS patient and ask if it looks like a KS lesion. Go to your own doctor. Don't start treating the person with KS as someone who has all the answers.

lovers of a person with AIDS, KS, or pneumocystis pneumonia? There are reports of diagnosed persons coming home and being ostracized from the kitchen or from the apartment or house all together.

That's a real serious, terrified reaction. I see that as a terrible problem for the person who's reacting that way. Obviously that person is not reacting rationally. Anyone who responds with that much fear is not taking responsibility to find accurate information and to act on it.

We know that AIDS is not transmissible through the air from one person to another. If it were, AIDS would be hitting many different population groups. AIDS has to be transmissible by some body fluid, a body secretion or excretion or blood. We're assuming that it's transmissible by intimate physical contact, probably sexually. People who are not gay men but have worked with gay men have not gotten the disease.

A roommate who is not being sexual with an AIDS person doesn't have to be concerned about contracting the disease from that person. It's o.k. to share a kitchen. Be careful to wash the dishes well, and don't share glasses and silverware before they're washed. It's sufficient to wash dishes in hot, soapy water. All you have to do is wash them, and there's no problem. You don't have to go through elaborate isolation techniques.

It's o.k. to share a bathroom and a sink with a roommate who has AIDS. It's probably not a good idea to share a toothbrush or a razor blade. With the razor a person might nick himself and get some blood on the blade.

Helen, the KS Clinic does not discourage sexual activity. It's known that the clinic even has a limited supply of rubbers available for KS patients. What do you tell your patients about having sex with their lovers or with others?

We tell our KS patients that even though they may no longer be carrying the assumed organism anymore, we don't know. It's only fair that they should tell their sexual partners that they have AIDS. We also suggest that they only be sexual in ways that do not share the body's secretions and excretions. That's very limited, and it can be very difficult for someone to drastically alter his sexual practices. But we acknowledge the importance of sexuality, and we're not expecting all the patients to stop being sexual. A year ago, that was the advice of doctors to many patients. All it did was cause many patients to go cold turkey, but when abstaining got to be too much pressure they were sexual anonymously. In situations where they didn't take appropriate precautions, creating guilt for them and panic for the gay men's community at large.

For lovers of patients the most important thing is to talk about the issues that come up. Even though previous sexual contact does not necessarily lead to a diagnosis of AIDS, there's a great deal of fear that can come up for someone who has been sexual with a patient. Talking about these feelings is very important. Do not be afraid to discuss the logistics of being sexual; don't avoid discussing how difficult all this may be.

The use of condoms or rubbers is suggested for two reasons: one, there is the possibility of transmitting AIDS through semen; and two, most AIDS patients are actively shedding the CMV virus (in their semen). It's probably not good for their partners to receive these secretions of CMV. Generally, for everyone, the use of rubbers could make rectal intercourse much safer, not only as protection against AIDS, but also against hepatitis B, syphilis, gonorrhea, venereal warts. If a person does use a rubber, care should be taken to use good rubbers that are made well and won't break easily.

While the use of condoms might permit anal sex, there doesn't seem to be any way to suggest safe methods for oral sex.

Yes, that's true. That's a major limitation. We also advise against deep kissing. But it is possible to kiss every part of the body other than the mouth and the genitals.

Some private physicians are instructing their AIDS patients to begin practicing celibacy. Those

sexual expression. These suggestions of celibacy seem to say more about the physicians' attitudes toward sex than about possible sexual practices for AIDS patients.

Yes, it's easier to say, "You need to be celibate" than to talk about sexual activity and especially about homosexual activity. It might be uncomfortable for some physicians to talk about sexual activity at all. We need to be more explicit about permissible, suggested sexual activity both for AIDS patients and for all gay men.

The KS Clinic also sponsors monthly informational meetings for those with KS.

Yes, once a month the patients get together with the doctors to ask questions. We also arrange for a speaker to address particular issues, such as the immune system, nutrition, sexual practices, mouth care, etc.

Helen, how do you personally cope with this experience? You're aware every day of the increasing numbers of people with KS and AIDS; and you counsel these people and monitor their treatments. You appear sensitive to their needs and concerns. How do you cope with the fear and how do you avoid burn-out?

I talk with other people who are also dealing with AIDS. I think it's really important that we all turn to each other when it gets really intense. Some days when I'm having a difficult time, I get on the phone and call my friends at Shanti or the health department and simply say, "Help!" I also get a lot of support from KS patients.

I worry about getting AIDS myself. I draw blood on patients, and I sometimes worry about that. I watch myself have irrational fears and I watch myself have rational fears. Usually I can maintain the separation of irrational fears.

I try not to take this home with me. The major things I try to do are to exercise frequently, get enough sleep, and eat well. I try not to get my whole life involved with AIDS. Most importantly, and I can't emphasize this enough for everyone else as well, I keep talking with people. I ask for and give support.

Possible AIDS Symptoms:

Swollen Glands. (enlarged lymph nodes) With or without pain, usually in the neck, armpits, or groin.

Pink to purple flat or raised blotch or bump: These are without pain, on or under the skin, inside the mouth, nose, eyelids, rectum. They have appeared recently, usually small but gradually getting bigger. They may look like a bruise that doesn't go away. Usually they are harder than the skin around them.

Weight loss: Unexpected and greater than 10 pounds in less than 2 months.

Fever: That has persisted for more than a week.

Night Sweat: Periods of waking up drenched or sweaty over several weeks.

Cough: Persistent, often a dry cough that is not from smoking and has lasted too long to be from flu.

Diarrhea: Persistent and not explained by other causes.

ONE OR MORE OF THE ABOVE MAY BE CAUSE FOR CONCERN.

Go to a doctor who is up-to-date on gay health concerns. If you have suspicious blotches or bumps, ask when you make the appointment whether your doctor is able to recognize Kaposi's sarcoma and if the doctor has the equipment in the office to biopsy a spot that is suspicious.

The UC San Francisco Dermatology Clinic (Ambulatory Care Clinic, 1st floor, 400 Parnassus, 666-2051) and the SF General Hospital Dermatology Clinic (SFGH Main Hospital Bldg, 3rd floor, 821-8096) can both usually make appointments within two weeks.

Wait of one or two weeks is not going to make a difference medically. If a biopsy is performed, the results will take a week to 10 days to come back. The waiting period is necessary and will not make a difference medically.

Information Services:

Kaposi's Sarcoma Foundation—514 Castro Street, 864-4376.

Bay Area Physicians for Human Rights—673-3189 (for physician referral)

Health Center I—3850 17th Street, 558-3905 (also 4 other Health Centers in the city)

AIDS Clinic at SFGH—1001 Potrero Ave, Ward 5B, 821-8153

KS Clinic at UCSF—Clinics Bldg, 400 Parnassus, 5th floor, 666-2051.

Other Support Services:

The Shanti Project—a volunteer counseling service assisting persons with life-threatening illnesses, their families, and friends. Support groups for potential patients who are waiting for biopsy diagnosis or who have recently been diagnosed with AIDS. 890 Hayes Street, 558-9644

SF General Hospital Psychiatric Emergency Clinic—1001 Potrero Ave, Emergency Room, 821-8125 (24 hour service)

Mission Mental Health—810 Capp Street, 558-2071 (M-F, 8:30 am to 11 pm)

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contrast was so stark.

And certainly the late-at-night walking the halls. I remember one of the early AIDS specials on TV, and it was on in Mark's room, and I didn't really feel like watching that. I just walked up and down the hallways, but it was on TVs in lots of people's rooms. *I felt deeply saddened by the enormity of what was happening to us*

Hughes: Was Mark watching it?

Helquist: I think he probably was. It was just that really odd feeling of having all this swirling around you. Sort of unreal that you're even there in the midst of it.

Hughes: Well, hospitals are unreal places to begin with.

Helquist: Yes, very much so.

see separate page
His parents who lived in New York came out to visit several times, and there was just so ~~pl. complete~~ initially a period of adjustment as his mother and I grew accustomed to each other.
Tensions between Friends and Parents

Helquist: One of the dynamics that was becoming more prominent is that a gay man's support circle, men and women, would organize

Hughes: Really? Because one of the points that was made in the grant application was that the fee-for-service method of payment produced a lot of problems--cash flow problems, training problems, etc.

Martin: Yes. And it's contrary to what is being done now on capitated arrangements. What people are doing in capitated arrangements is saying, "Here's your lump sum of money for this population and you take care of them, whatever their requirements are; it's your problem, not ours." Fee-for-service says, "Your incentive is to make as many units of service as possible, because we're going to pay you by the unit of service," which in homecare is a visit. So the fee-for-service system has less incentive ^{to be cost} effective, ^{even though there are controls over it in managed} care.

Differentiating and Amalgamating Home-based Programs

Hughes: How do you differentiate the activities of the three organizations that are involved in AIDS community care: the VNA, Home Health Services of San Francisco, and Hospice?

Martin: You're taking information from the 1984 letter, which didn't exist after that. Well, there's history around VNA of San Francisco and its mergers. In 1981, the San Francisco Home Health Service merged with Hospice of San Francisco, and in 1983, those services together merged with VNA of San Francisco. ^{The parent corporation became known as VNA, Inc.} VNA of San Francisco provided traditional intermittent home ^{health} care services, which means people whom we expect to get better are going to get services. Hospice of San Francisco provided care to people who were

was a need for a social worker, that ~~these~~ people coming to the ^{KS} clinic needed to have assistance with applying for various benefits; they needed to have some help from a social worker. I was told that we couldn't have a social worker, that the KS Clinic was not making money for the university; it was not an official clinic. ^{They told me that if} ~~As I said before,~~ ^{if} they had their way, if I was actually a clinic staff person, then I would be assigned to be in charge of a number of clinics. I would never have the luxury of having just the small patient load that I was in charge of.

So I didn't feel supported by the university, and I didn't feel that the ^{patients} ~~people~~ who came to the clinic were supported by the university. It was a very different-looking clinic than what ^{eventually} evolved at San Francisco General, the AIDS Clinic. ^{The difference was that} ~~The only reason that was different looking was~~ ^{at San Francisco General} ~~because~~ there was extra funding from the city to provide the additional staff to meet the complex needs of the patients.

Social Services

Hughes: As you explained to me off-tape, if you look at patient care as a spectrum, what the KS Clinic was able to do was only a very small part of that spectrum, which when the AIDS Clinic at San Francisco General was up and running, it could

Sally Smith Hughes

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